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# Developing A Chronic Pain Vocabulary: Communication Preferences Among Individuals With Chronic Pain

Karin L. Becker

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DEVELOPING A CHRONIC PAIN VOCABULARY:  
COMMUNICATION PREFERENCES AMONG  
INDIVIDUALS WITH CHRONIC PAIN

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A Dissertation

Submitted to the Graduate Faculty

of the

University of North Dakota

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August

2015

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This dissertation, submitted by Karin L. Becker, in partial fulfillment of the requirements for the Degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

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July 7, 2015

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## ABSTRACT

In order to be acknowledged, chronic pain must be voiced yet disclosing of chronic pain is fraught with social and professional repercussions. Moreover, there is a perceived disinterest in hearing about, and a stigma associated with the experience of chronic pain. This research explores the therapeutic value of communicating about pain. Nineteen individuals with chronic pain participated in a six-week online writing workshop to describe the way chronic pain impacts daily activities. These qualitative responses were analyzed using discourse analysis and four interpretive repertoires emerged which convey the multi-faceted impacts of living with chronic pain. These findings informed the creation of a quantitative survey tool which was widely disseminated using social media to chronic pain dedicated forums and websites.

Findings indicate that audience and gender have a large sway on communication preferences. Individuals with chronic pain desire to receive cure-centered information from health care providers and care-centered information, including empathy, from family and friends when they communicate about their pain. Women in particular aspire to receive emotional support for their well-being and empathy upon communicating about their pain. These results help to fill in the void of patient communication preference within the framework of delivering patient centered care. Understanding patients' communication preferences has high clinical value as providers can tailor their communication practices to increase rapport, improve patient satisfaction and promote treatment adherence. They place a heightened role on family and

friends in the treatment plan as they can offer needed emotional support. Implications include educating family and friends to be aware of pain behavior so they can recognize early indicators and provide empathetic responses. Additionally, using computer mediated communication is a recommended platform to engage individuals with chronic pain due to its convenience, low-cost, and anonymity as well as its potential to connect disparate individuals and build community among marginalized group.

## **CHAPTER ONE**

### **INTRODUCTION**

The invisible and inaudible nature of pain requires that sufferers convey to others that they are feeling pain (Jackson, 2005). While pain must be voiced, in verbal or non-verbal accounts, to be acknowledged disclosing of pain conditions is fraught with social and professional stigmas (Gifford, 2013; Sisk, 2007; Hilbert in Jackson, 2005). A social consequence of talking about pain is risking the label of whiner, complainer or malingerer (Werner and Malterud, 2003). Despite the American Disability Act (1990), there are subtle areas of discrimination in the workplace that discourage employees to disclose of their pain conditions for fear of being perceived as lazy, incompetent or not team players, (Bouton, 2013). Often, the voices of individuals with chronic pain are invalidated, silenced or overlooked (Good, 1992; Werner, Isaksen & Malterud, 2004; Jackson, 2005)

Therefore, this study proposes to contribute to the knowledge base of patient-provider communication by exploring the ways in which individuals with chronic pain currently communicate versus how they prefer to communicate about their chronic pain. A thorough review of patient-provider communication will attempt to shed light on communication interactions and disclosure practices historically as well as current trends. Inherent in this review will be a gender lens which will provide metaphorical glasses with a special filter that highlights women's realities, needs and perceptions when viewing the way men and women experience and are treated for chronic pain (Clift, 2011).

To explore patient-centered communication preferences, I argue that new methodologies and approaches are needed that depart from positivistic, clinical research and embody a social constructivist, inclusionary and open-ended dialogic perspective. This research tests the ability of this approach to cater to patient-centered environments that are conducive and convenient to enable patients to openly disclose of their pain identities, using language that is their own, in a safe and secure setting of like-minded sufferers. To implement this approach, a mixed methods research design will be employed that is sequential exploratory in nature. The first phase of the research process will consist of collecting textual responses that have been posted within an online creative writing workshop and analyzing them using discourse analysis. This qualitative data will then inform the second phase of research collection, the development of a quantitative survey tool (See Appendix L). The survey will be broadly disseminated using computer mediated technology to both men and women who suffer from chronic pain.

Before patient-centered communication practices and preferences can be examined, I will first discuss how chronic pain is understood and who is primarily affected by it. Therefore, an introductory look at obstacles to communicate pain, attempts to define pain and attempts to gender pain follow in the subsequent sections.

### **Overview of Chronic Pain**

Chronic pain is a common, confusing and costly health care problem. According to the World Health Organization (WHO) chronic pain is one of the most underestimated health care problems in the world today, having a significant impact on the quality of life of individuals and a major burden on health care systems (WHO, 2004). More than 1.5 billion people worldwide suffer from chronic pain and in the United States, the incidence rate is about 116 million adults (Institute of Medicine of the National Academies Report [IOM], 2011). Narrowing the scope of

chronic pain to focus on its impact in the United States of America shows the influence it has on a nation. The American Academy of Pain Medicine (n.d.), reports chronic pain affects more Americans than diabetes, heart disease and cancer combined.

Key findings from the Voices of Chronic Pain survey (2006) reveal that as a result of pain, more than half of the respondents (51%) reported having no control over their pain. In terms of assessing the impact chronic pain has on respondents' quality of life, nearly two-thirds (59%) reported pain impacting their overall enjoyment of life; more than three-quarters (77%) reported feeling depressed; 70% said pain impacted their ability to concentrate; 74% reported decreased energy levels; and 86% reported an inability to sleep well (Voices of Chronic Pain Survey, 2006).

Due to its prevalence, seriousness, rates of under-treatment across population groups, and cost, the Institute of Medicine's "Reliving Pain in America" report conceives of pain as a public health challenge facing the United States (IOM, 2011). Demographic trends among chronic pain sufferers include a higher prevalence among women and senior citizens, and those having a lower socioeconomic status (Blyth, 2010). Those aged sixty- five and older report longer periods of pain and often have permanent pain that they live with for the rest of their lives (Wertich, 2014). Given the population dynamics and demographic shifts of aging Baby Boomers, the Institute of Medicine forecasts that the prevalence of pain in the U.S. will likely continue to rise (IOM, 2011). These trends shed light on a growing public health crisis (Blyth, van der Windt, & Croft, 2010; IOM, 2011).

Financially, the annual national costs associated with treating chronic pain ranges between \$560 to 635 billion annually (Gaskin & Richard, 2012). This estimate includes the direct costs of treating pain as well as the indirect costs of lost productivity such as hours and

days of work, reduced performance and reduced wages. Compared to other chronic diseases such as heart disease, hypertension and respiratory diseases, the cost of treating chronic pain is far greater: \$28 million, \$86 million, and \$108 million more respectively (Azevedo et al., 2014). On an individual level, chronic pain interference was associated with approximately \$3,700 annually in total adjusted expenditures over no pain interference, largely attributed to inpatient and hospital outpatient costs (Stockbridge, Suzuki & Pagan, 2014). These results show that chronic pain is associated with a sizable increase in personal expenses (Stockbridge, Suzuki & Pagan, 2014).

Chronic pain has been shown to be a major contributor to increased health care utilization, reduced labor productivity due to work absenteeism, early retirement, and job loss (Azevedo et al., 2014). Unrelieved chronic pain often results in patients having longer hospital stays, increased rates of re-hospitalization, and decreased ability to function and maintain employment (American Academy of Pain Medicine, 2013). The U.S. represents the largest market for pain management worldwide with pain prevention as well as treatment among the top health care concerns (Global Industry Analysts, 2011). Future trends in pain management show a market decline during 2012 and 2018 due to patent expirations of major revenue-earning drugs and an increase in over-the-counter non-narcotic analgesics (Tylenol) used to overcome chronic pain (Pain Management Therapeutics Market, 2013). From this cursory overview of the incidence rate and financial impact of chronic pain, and given population dynamics and demographic shifts in the U.S., research suggests chronic pain has and will continue to receive much attention (Stockbridge, Suzuki & Pagan, 2014; IOM, 2011).



## **Communication Practices**

When the field of chronic pain is narrowed to focus on communication practices, a review of the literature shows a wealth of information centering on patient-provider interaction (Ong et al., 1995; Tongue, Epps, & Forese, 2005; DiMatteo, 1998). Studies of doctor-patient communication tend to approach the research in clinical environments where the biomedical model sets the research agenda (Beck, Daughtridge, Sloane, 2002; Ong et al., 1995; Baillie, 2009; Walsh & Kowanko, 2002).

Within the patient-provider communication paradigm, researchers have documented communication interactions between providers and patients. Within this body of literature, numerous studies have focused on: a) how information is exchanged (Ong et al., 1995; Ha & Longnecker, 2010; Roter, Hall & Katz, 1988); b) benefits of improved communication skills (Maguire & Pitceathly, 2002; Hall, Roter & Rand, 1981; Roter, 1983; Tongue, Epps, & Forese, 2005); c) barriers to effective communication (Fentiman, 2007; (DiMatteo, 1998; Maguire & Pitceathly, 2002; Duffy et al., 2004); and d) strategies for effective communication (Ha & Longnecker, 2010; Teutsch, 2003; Lee et al., 2002). While this research has provided valuable information to better understand the content and benefits of the communicative exchange between providers and patients, I recommend that more focus be devoted on patient-centered communication practices and preferences.

A shift to the patients' perspective prioritizes the patients' voice and views. The need for a more patient-centric perspective is rationalized by the fact that a provider's ability to diagnose and alleviate pain is contingent on the opportunity and ability of sufferers to communicate their pain to a health care provider (Narayan, 2010). The focus on the communication exchange is needed as Ruesch (1963) states communication is the primary means by which individuals

influence and understand one another. Since pain occurs in the interiority of the body and physical manifestations are often absent (Birk, 2013), I propose that more attention be placed on the process of how providers elicit information from patients.

### **Obstacles to Communicating About Pain**

The task of evaluating others' pain is what Prkachin, Solomon and Ross (2007) call a case of decision-making in uncertainty. While physicians tend to focus their communication efforts on gaining information in order to diagnose and treat their patients many barriers exist that impede the provider-patient exchange (Ong et al., 1995). Patients' anxiety levels, educational background, and communicative style may impede the communication exchange (Street, 1991). Research has shown that patients seem to be reluctant to talk about their pain (Francke & Theeuwen, 1994). Pain's variable nature makes it difficult to for sufferers to perceive and describe with exact communication which can lead to difficulties in pain assessment and management (Shapiro & Teasell, 1997).

Nurses are usually on the front lines of observing and assessing patients' pain and studies have concluded the way pain is discussed between nurses and patients leaves much to be desired (de Rond, de Wit & van Dam, 2000). More often than not, nurses tend to underestimate patients' pain (Prkachin, Solomon, & Ross, 2007; Field, 1996), under-assessing severe pain and over-assessing mild pain (Zalon, 1993). The discrepancy between patients' pain and nurses' estimation of patients' pain is greater for patients with chronic pain than acute pain (Teske et al., 1983).

Various instruments have attempted to objectively measure pain such as the pain numeric rating scale (NRS) on which patients rate their pain intensity on a 0-10 scale, with zero representing "no pain" and ten representing "worst possible pain." The NRS has become the

most widely implemented instrument for pain screening; however it is reported to only have modest accuracy for identifying patients with clinically important pain in primary care (Krebs, Carey, & Weinberger, 2007). Major problems in the measurement of clinical pain exist because of a limited number of reliable and valid instruments can measure the experience of pain (McGuire, 1984). While instruments can measure intensity, behavioral and/or physiologic phenomena associated with pain, they cannot speak to the lived experience of pain (McGuire, 1984). Dr. Gregory Kosmorsky, head of neuro-ophthalmology at Cleveland Clinic, emphasizes some of the frustrating issues of making a diagnosis, “Pain cannot be quantified, which makes it an enigma, and it is colored by emotion and by previous experience. Pain is difficult for us as physicians to deal with” (Phillips, 2008, sec. 2).

The invisible nature of pain puts the onus on the sufferer to articulate it (Scarry, 1985) yet without expressing pain, it remains a personal and private phenomenon (Jackson, 2005). The ability to communicate the internal world of feelings and thoughts is made possible through language which is understood as a symbolic system of signs. Language has the power to shape the way we see and think of things (Lakoff & Johnson, 1980) and is the medium in which a self is socially constructed (Weedon, 1987). The words we use help to fashion our identity; our values, norms and predispositions are embedded in our vocabulary (Berger & Luckman, 1966). Yet the task of communicating chronic pain is hampered by the problem of standardized descriptors used in clinical settings not necessarily matching patients’ own language (Tarr, 2014). As Belenky et al. (1986) argue, their inability to access their language may also decrease the likelihood of using their own bodily constructed knowledge as a source of validation.

## **Defining Pain**

As pervasive as chronic pain is, it is also perplexing. Coming to a consensus on the definition of pain is complex, as pain is a multidimensional experience that has neurophysiological, biochemical, psychological, ethnocultural, religious, spiritual, cognitive, affective, and environmental aspects (Larner, 2013). Due to its subjective nature, establishing a “definition of ‘pain’ that is agreeable to all people is a near-impossible task” (McCool, Smith, & Aberg, 2004, p. 473.)

Definitions for chronic pain vary depending on who is defining them. A driving force in the biological sciences has been positivism, a term popularized by Auguste Comte’s third phase of intellectual development which consists of scientific inquiry as governed by the scientific method (Fulcher, 1979). Positivism has an ontological position of realism where objects have an existence independent of the knower (Cohen, Manion, & Morrison, 2007). As will be discussed in more detail in the literature review, positivism has attempted to account for all knowledge from the scientific world view which asserts the objective realm is the only legitimate domain of inquiry (Mehta, 2011). Knowledge about an objective reality is discovered impartially where the researcher is a separate entity from the researched (Scotland, 2012). In this conceptual framework, an underlying belief is that the biological body is fixed, made up of systems (nervous, endocrine, immune) which function in prescribed and predictable ways to maintain homeostasis; this idea serves as the grand narrative in scientific literature (Shilling, 1993; Morris, 1998).

Given this fixed idea of the body and tendency for scientific prediction and control researchers and physicians can provide a definition of pain that entails criteria for duration and frequency of symptoms (Morris, 1998). The International Association for the Study of Pain

provides a working definition of pain as “an unpleasant experience that accompanies both sensory and emotional modalities and has an apparent lack of biological value, meaning the pain has persisted beyond the normal tissue health time”; it may or may not be accompanied by identifiable tissue damage and is influenced by multiple factors, including cognitive, affective and environmental (Merksey & Bogduk, 1994, p. 209). The Institute for Clinical Systems Improvement (ICSI) adds on to this definition of chronic pain by stating it is “persistent; either continuous or recurrent, and of sufficient duration and intensity to adversely affect a patient’s well-being, level of function, and quality of life” (Bradley et al., 2013, p. 218) From this definition, the ISCI highlights the impact pain has on an individual more so than the biological impact pain has on the body.

The duration of pain also serves as a defining tool. If pain lasts less than three months, it is termed acute; pain or discomfort that persists continuously or intermittently for longer than six months is termed chronic (Elliott et al., 1999). The most common sources of chronic pain stem from back pain, joint pain, sinus pain, migraines, or pain from an injury (Nazario, 2010). Other common chronic pain conditions include fibromyalgia, rheumatoid arthritis, chronic fatigue syndrome and endometriosis (Medicine.net, 2012). Bradley et al. (2013) determined there are three main biological sources of pain which include 1) neuropathic, meaning pain arises as a direct consequence of a lesion or disease affecting the somatosensory system; 2) peripheral which includes HIV, metabolic, and phantom limb pain; and 3) central which includes Parkinson’s disease, multiple sclerosis, post stroke pain, and fibromyalgia syndrome.

Even if certain conditions are classified as chronic pain, pain is a category signifying a multitude of different experiences. Pain is a necessary biological warning signal with the purpose of alerting the individual of an impending or already existing injury (Ghallagher, 1999).

However, when pain persists over longer periods and becomes chronic, it usually loses its purpose as a warning signal and becomes not only a sensory experience, but an end result of a complex process including physical and psychosocial factors that affect a person's health-related quality of life (Jonsdottir, 2013).

While most people perceive pain as a symptom, chronic pain is a disease in and of itself; untreated pain can result in nerve damage that never heals, which leads to chronic pain (Wertich, 2014). The way pain is perceived in the brain affects the way pain impacts life experiences; cognitive and emotional centers of the brain can influence pain perceptions (Tracey & Mantyh, 2007; Wertich, 2014). The association between the effects of long-term pain and cognitive performance has been the subject of a recent study by Baliki et al. (2008) who found that cortical areas of the brain were harmed by the effects of long-term pain, implicating that brain disruptions may trigger the cognitive and behavioral impairments accompanying chronic pain.

Individuals with chronic pain are more than likely to suffer not only from physical pain, but may also experience psychological problems including depression, anxiety, personality disorders, sleep disturbances, decision-making abnormalities and post-traumatic stress; these comorbidities can affect the course of pain treatment (Apkarian et al., 2004). If patients present with psychological disorders the ability of the patients to successfully complete treatment is hampered (Bradley et al., 2013). Individuals with chronic pain lose the ability to adapt as constant pain makes a person more petulant and irritable and chronic stress may arise (Lago-Rozzardo et al., 2013). Some of these factors relate to the progressive characteristics of pain, including severity, location, spread, duration, and pattern, and their impact on people's lives (Tripp, VanDenKerkhof, & McAlister, 2006). As Richardson, Ong and Sim (2008) state, "Living

everyday life with widespread pain is not simply about *experiencing* pain in a daily context, but is also about *managing* the pain in the context of daily routines and activities” (p.1).

Coming to a consensus on the definition of pain is complicated; this operationalized definition clearly delineates what constitutes chronic pain from acute pain and is useful in outlining the scope of impact chronic pain may have. This overview of what constitutes chronic pain and how it affects cognitive and psychological functioning provides a perfunctory understanding of chronic pain. An examination of who pain primarily affects will shed light on the need to integrate a feminist perspective.

### **Gendering Pain**

Since the 1990s, a substantial amount of scientific and clinical interest has been devoted to exploring sex-related influences on pain (Fillingim et al., 2009). Roughly one-third of Americans experience chronic pain, and a disproportionate number of these are women; women also face a significantly greater risk of developing a pain condition (Elliot et al., 1999; Edwards, 2013). Women are at greater risk to have migraines; oral and abdominal pain; twice as likely to have multiple sclerosis; two to three times more likely to develop rheumatoid arthritis; and four times more likely to have chronic fatigue syndrome (Fillingim et al., 2009). Men are more likely to have lower back pain, which may originate from a work-related injury, disease or stress. A study examining the prevalence of chronic pain in the US population by age sex and race portrays the average chronic pain sufferer to be a white woman, aged 50, who experiences pain in her back, followed by legs and feet (Hardt et al., 2008).

Differences exist in the ways in which men and women perceive, express and tolerate pain (Miller & Newton, 2006). Psychosocial factors such as sex role beliefs, pain coping strategies, mood and pain-related expectancies may motivate these effects (Fillingim, 2000).

Gender roles play a large part in how pain is expressed, with the masculine gender norm conveying an increased tolerance of pain and the feminine gender norm conveying an acceptance of pain as a normal part of life and greater pain expression (Unruh, 1996). Men also have a different approach to reporting pain. Kugelmann's (1999) study on working class men and women with chronic pain indicates that women are more inclined to passively accept pain as their lot in life while men are more likely to view it as a form of a complaint they want to file against someone or some company (Kugelmann, 1999). Cultural and familial factors can influence pain responses and expressions (Fillingim, 2000).

With an increased likelihood to have chronic pain, the way women communicate pain deserves further attention as diagnosis and treatment are all hinged on pain communication. Moreover, there is a disproportionate gender ratio of practicing physicians in the United States. According to information gathered by the Henry J. Kaiser Family Foundation, females represent only 32% of practicing physicians (Kaiser Family Foundation, 2014). Overall, for respondents indicating gender there are nearly twice as many male physicians than females (Kaiser Family Foundation, 2014). Therefore, gender differences exacerbate the reporting of chronic pain on two accounts: a higher incident rate and greater pain expression for women. A review of the way women experience pain and are treated for pain, from both positivist and feminist approaches, will attempt to shed light on the gendered nature of pain. While I am aware that men experience chronic pain and while my intention is not to focus only on women's pain, given the disproportionate ratio of women affected by pain, this research attenuates focus on gender specific communication preferences when communicating about pain.



## **Research Questions**

This research will attempt to answer the following questions:

RQ 1: How does communicating with medical providers influence communication preferences among individuals with chronic pain?

RQ 2: How does communicating with non-medical providers influence communication preferences among individuals with chronic pain?

RQ 3: How does the gender of an individual suffering from chronic pain influence communication preferences with medical providers?

RQ 4: How does the gender of an individual suffering from chronic pain influence communication preferences with non-medical providers?

## **Audience Specific Communication Preferences**

In regards to pain communication preferences among individuals with chronic pain, the first two research questions delve into the extent of influence that audience and context have on the communication exchange. Discourse will change depending on the setting, with tone and turn-taking adjusted for the appropriate context (Gee, 2014). In a clinical environment communication patterns are governed by the hierarchy inherent in a provider-patient relationship where turn-taking favors the expert role of the physician and communication resembles a formal question and answer format with providers asking the majority of the questions (Roter, Hall & Katz, 1988). When individuals with chronic pain communicate about their pain with family and friends, the casual and familiar environment as well as the rapport established with family members enables more open-ended conversational communication.

While the external environment does have sway on the communication transaction what is unknown are the communication outcomes sought by individuals with chronic pain when they

communicate their pain. Research question one examines what types of communication chronic pain patients would like to receive upon communicating about their pain with their health care provider. In particular, do patients desire more of what Ong et al. (1995) classify as cure-centered type of communication, which focuses on information and instructions on treatment, or do they prefer more care-centered communication which involves receiving more emotional support and empathy? Survey question 17 corresponds to it.

Obtaining useful and relevant information about one's pain and treatment can fulfill knowledge gaps, reduce uncertainty, and relieve anxiety (Ha & Longnecker, 2010; Ong et al., 1995). In this light, gaining knowledge may be viewed as therapy and could serve as the underlying motivation for pain expression. Alternately, pain communication may be determined to be of therapeutic value when individuals receive validation and emotional support (Roter, Hall & Katz, 1987). In this way, gaining legitimation and the chance to be heard may serve as the underlying motivation for pain expression.

Similarly, research question two inquires what types of communication offerings do individuals with chronic pain like to receive upon disclosing of their pain or discussing its impacts with non-medical others, particularly family and friends. Survey question 18 corresponds to it. Learning of these communication preferences can help the various audiences to tailor their communication offerings to better support their patients and loved ones. For example, given the abbreviated office visits, if health care providers knew that generally, patients with chronic pain looked to them for emotional support then they may be able to allocate their office visit to allow for attentive listening and empathetic responses and print up treatment information for the patient to take home. Alternately, if the findings show the reverse, then providers may want to use their clinic visit to ensure the patient understands their information. As reported by

Roter, Hall and Katz (1988), only six percent of provider-patient interaction is allotted to question-asking. More time devoted to confirming patient comprehension of diagnosis and treatment may yield powerful results for health treatment outcomes. This effort to place more time on instrumental communication is congruent with the teach-back communication mechanism in which the patient repeats back the treatment information in their own words to confirm that the provider has explained what they need to know in a manner that the patient understands (Schillinger et al., 2003).

Learning of communication preferences for family and friends also has value in that they can play a large role in helping the individual with chronic pain make sense of their diagnosis and treatment. As Lincoln and Guba (1994) posit, knowledge is constructed together; therefore talking about their pain with others helps them to process their information and construct their identity (McConnell-Ginet, 1980; Weedon, 1987). To delineate the extent pain communication seeps into social discourse with family and friends I will narrow the scope of the setting and inquire if individuals talk about pain with non-medical others in a non-medical context. Responses to this question can assist in gauging the extent individuals with pain disclose of pain identities and survey questions 7 and 8 correspond to it.

Knowledge of communication preferences among individuals with chronic pain can be powerful to friends and family as individuals with pain may not choose to communicate their pain. Since individuals with chronic pain can "pass" as "normal" people (Joachim & Acorn, 2000) and in the absence of a physical symbol of pain (cane, crutches, wheelchair, limp, etc.) individuals are not "marked" or "othered" (Butler, 1993). Therefore, there may not be a visual cue that prompts others to acknowledge or inquire about their pain. The decision to talk about their pain rests entirely on the sufferer and they therefore have the choice to conceal or reveal

their pain identity. The pervasiveness of the effects of chronic pain, impacting all aspects of a person (Larner, 2013) makes chronic pain a potentially rich topic for further research in the field of communication yet it may require non-medical others to facilitate this communication by inquiring about their pain.

For individuals with chronic pain, pain colors decision-making and planning so the likelihood of talking about pain is high. Yet given the social stigma and potential professional repercussions from disclosing of pain, the desire to talk about pain may be diminished (Bouton, 2013; Holloway, Sofaer-Bennett, & Walker, 2007; Kleinman, 1988; Hegarty and Wall, 2014). Concealing brings about isolation, loss of voice and disempowerment (Asbring & Narvanen, 2001). Revealing brings about the potential of community and empathy at the expense of stigma and social and professional repercussions (Bouton, 2013). Tension exists when disclosing of pain but if family and friends knew which types of information and responses provide emotional support and therapeutic value, their communication exchanges may alleviate some of the pressure. These research questions potentially assist in unpacking the latent conventions embedded in the communication exchanges and notions of therapeutic value in talking about pain.

### **Gender Specific Communication Practices**

The third and fourth research questions examine the differences in communication preferences between men and women when they are communicating with medical providers and non-medical providers. While research has already demonstrated women are more likely to experience chronic pain (Elliot et al., 1999; Cepeda & Carr, 2003; Edwards, 2013), and are more likely to communicate pain (Unruh, 1996), men's preferences should not be excluded. These results will help to shed light on the disclosure preferences for women, in comparison to men. If

differences are known and accounted for, the ability for health care providers to tailor their communication exchanges can positively impact patient understanding, rapport and treatment outcomes (Maguire & Pitceathly, 2002; Hall, Roter & Rand, 1981). Attending to gender-specific communication practices is one way providers can deliver personalized treatment and help patients feel they are being heard and understood. Moreover, patients who have the opportunity to disclose of their pain have an increased sense of self-efficacy and confidence in their outcomes (Stewart et al., 2000; Teutch, 2003). Given the previous, learning what types of prompts may trigger pain disclosure can facilitate pain communication for both male and female chronic pain patients.

### **Language Assumptions**

All research questions are hinged on an assumption that language is available or adequate to the patient or individual with chronic pain to convey the subjective and invisible sense impressions of pain. In a social constructivist perspective, language is not representational, but constitutive (Berger & Luckman, 1966). As put forth by Davies (1989), individuals are constituted and shaped by the language they use. According to Price and Cheek (1996) the scientific-medical discourse is one discourse, albeit a powerful one, which places focus on the patient's self-report of pain and the measurement of that pain, not the patient as a person. With the focus on the patient's self-report Shapiro and Teasell (1997) identify a problem in that the abstract and personal nature of pain exacerbates patients' ability to convey its sensation with precision.

If individuals with chronic pain choose to reveal their chronic pain identity by talking about it, and if they succeed in using language to adequately convey their pain, the benefit for taking the risk of disclosure may be questionable. Individuals who try to communicate their pain

and are subsequently misunderstood may feel rejected or alienated (Garro, 1992; Raymond & Brown, 2000). Moreover, although simply talking about pain may not make the pain go away research has shown that individuals with pain long to feel validated and supported (Becker, 2013).

It is possible there is a lack of congruence between providers and patients' frames of experience. Often, patients use language and metaphoric expressions that provide rich descriptions of sensations, but do little to help providers with diagnosis (Jenny & Logan, 1996; Jairath, 1999). The dismissal of these insights by providers may make patients unwilling to disclose of their true feelings (Jairath, 1999). I propose to examine what types of questions would best serve as prompts to encourage patients to disclose. Survey questions 19 and 20 ask patients which questions will trigger pain communication and help facilitate better understanding of their pain by both providers and family and friends.

### **Online Health Seeking Behavior**

Since all four research questions will be explored using computer mediated communication through an online writing workshop and a survey disseminated via social media websites, I argue that the context of the Internet needs to be taken into consideration. The advent of Internet technology and the increased availability and credibility of medical and health care websites may influence patient motivations for seeking medical care. Prior research has shown that information seeking was the primary reason patients sought out medical care (Beisecker & Beisecker, 1990; Ong et al., 1995). However, most of this research was conducted in the early to mid-1990s, prior to the expansions of Internet technology. With the advances in Internet technology that have happened since then, there have been profound strides made both in accessibility and credibility among Internet sources.

First, Internet technology is widely available and accessed. The National Broadband Map indicates that nationwide, 98.6% of Americans have access to broadband wireless capabilities (National Broadband Map, 2013). According to the Internet Project compiled by the Pew Research Center, as of January 2014, 87% of American adults used the Internet (Pew Research, 2015). A further breakdown of usage patterns focusing on gender shows almost equal use (87% men and 86% women) (Pew Research Center, 2015). In terms of online information seeking behavior, women are more likely to search online than men (Higgins, 2011). Online health seekers tend to be more educated, earn more, and have high-speed Internet access at home and at work (Higgins, 2011).

Secondly, prices for Internet access have come down, with average monthly high speed costs ranging from \$14.95-34.95 plus taxes and fees, in North Dakota. Globally, average broadband Internet connections have been reduced by more than half according to research conducted by the International Telecommunications Union (Tan, 2011). Tan (2011) notes the richest countries in the world have the most affordable broadband connections.

Thirdly, with gaining Internet popularity for the past 25 years comes greater prevalence of websites offering health related resources; social media sites have become important sources of online health information (National Institutes of Health, 2013). As more people use the Internet as a source of medical information, webpage credibility and trustworthiness become of crucial importance (Jessen & Jorgensen, 2012). Website appearance has a large impact on attitudes of trust and credibility as consumers tend to trust attractive websites more than unattractive ones (Sauro, 2013). According to rankings from both global and U.S. traffic, WebMd, NIH, Yahoo! Health, MayoClinic and MedicineNet as the top five most popular health websites (eBusiness Guide, 2015).

While these trends show improvements in Internet accessibility and credibility, Internet access is influenced by more than infrastructural availability; education and social class also sway digital involvement. Recent data on the digital divide conducted by Lee Rainie, Director of the Pew Research Center's Internet and American Life Project, show that some of the factors associated with use and adoption of technology are age, household income, educational attainment, community type, and disability (Rainie, 2013). Specifically, age is the number one factor indicating use of technology as individuals aged 70 years and older are least likely to use the Internet; individuals who hold a college degree or higher and live in an urban or suburban community are more likely to use the Internet. Further Internet usage and adoption trends in the U.S. show that individuals who have a disability and who prefer to speak Spanish are less likely to use the Internet (Rainie, 2013).

While this data provides a profile for common Internet users, what also needs to be considered when discussing Internet trends is digital literacy. The opportunity to navigate the complex network of the World Wide Web where cybercriminals are anonymous and have a virtual market of available victims puts the onus on users to protect themselves through safe online practices (National Crime Prevention Council, 2012). When discussing Internet security, three common concerns are vulnerability inherent in the network and devices; threats that people are eager and willing to take advantage of them in the form of hackers, spammers, or phishers; and attacks in the form of worms, viruses and Trojan horses that deny Internet access (Bertino et al., 2010). Cyberattacks take an average of 31 days to clean up and remediate and security breaches have cost companies on average \$3.5 million in US dollars, including direct costs of notification and legal defense costs as well as indirect costs of loss of trust and lost customer business (Ponemon Institute, 2014). Given the rise in cybercrimes, with the US Director of



National Intelligence ranking cybercrime as the top national security threat, Internet users who lack digital training can be especially vulnerable (Clapper, 2013).

The concerns for Internet security and safety may deter some from interacting with Internet technology and prevent them from either accessing information or participating in an online writing workshop or web-linked survey. Millennials, those born from the early 1980s to early 2000s, and what is now being termed as the i-generation, coined by psychology professor Jean Twenge to be the subsequent generation, are more likely to have digital literacy skills that predisposes them to trust and navigate the Internet (Horovitz, 2012). For digital natives, those growing up with technology, maintaining good password management and installing anti-malware and antivirus software are common practices as they have been the recipients of strong digital literacy that comes from Internet education and training (Department of Homeland Security, 2015). Recent information technology curriculum has been created to prepare K-12 students for 21<sup>st</sup> century digital communication competency with a focus on cybersafety, cybersecurity and cyberethics (Pruitt-Mentle, 2008). The C3 framework provides skills so that students practice safe strategies to protect and promote themselves when using digital technology and are responsible for appropriate while using and accessing technology (Internet Keep Safe Coalition, 2009).

While this digital literacy is promising for digital natives, more Internet education may be needed for older Americans who have had to learn how to access and adopt Internet technology into their lives. According to Prensky (2001) digital immigrants, or those born before the 1980s, still hold a print footstep and turn to the Internet for information as a second choice, not as their first instinct. This familiarity or distrust with the Internet has important implications for my research design as my methods may favor digital natives yet the occurrence of chronic pain

impacts older individuals or digital immigrants. While the Internet has spawned a new following of medical information seekers, providing relevant and factual medical information in laymen terms, it is unclear if this information is bypassing the need to receive information from a health care provider.

To examine the influence of Internet technology on the chronic pain population, two survey questions inquire about the types of communication offerings respondents would like to receive from their health care providers and their family and friends. Specifically, by asking respondents to rank their preference of receiving information, support and empathy from medical providers, question 18 seeks to determine what individuals with chronic pain desire most from their health care providers. There is a possibility that with the ease of gaining health information online, patients are more informed and as a result, desire more affective and emotional support from their provider and friends. Question 19 helps to pinpoint the communication preferences from friends and families.

### **Method to Explore Research Questions**

To best explore these research questions a mixed methods research approach will be taken to produce a holistic picture and present both subjective and objective data (Creswell, 2008). Johnson and Onwuegbuzie (2004) claim the best way to learn more about a topic is through combining the strengths of qualitative and quantitative research while compensating for the weaknesses of each method. The intent of this mixed methods study will be to learn about communication preferences of individuals with chronic pain and it will be carried out in two phases, where the first method informs the second. Because one approach follows the second, and both are exploratory in nature, the approach is classified as sequential exploratory mixed methods (Creswell, 2008).

The first phase will be a qualitative exploration of communication practices by conducting an online writing workshop for individuals with chronic pain. A confidential and anonymous website will be created where individuals who share a common phenomenon of chronic pain can convene to discuss the experience and impacts of chronic pain. Textual responses posted to the workshop will be analyzed using discourse analysis. Then, based on the findings from the workshop, the second phase will involve developing an instrument and surveying individuals with chronic pain about their communication preferences with health care providers as well as family and friends. A quantitative survey will be created through Qualtrics, an online survey-based research platform which allows researchers to develop a customized survey instrument and get real-time results (Qualtrics, 2014). The survey will be disseminated online through chronic pain specific websites, Twitter feeds and other chronic pain social media sites.

To examine the influence of gender as stated in research questions three and four, an independent samples t-test will be run to determine the difference between two groups on one dependent variable (Creswell, 2003). Findings from the quantitative data will be analyzed to compare the dependent variable, disclosure preferences, against the independent variable, gender. Specifically, I will be examining if differences exist between men and women and their disclosure preferences.

The rationale for using both qualitative and quantitative data is hinged on the understanding that a survey investigating chronic pain communication preferences could best be developed only after a preliminary exploration of chronic pain communication practices has occurred. Qualitative data will be collected first to better understand participant language; the initial findings will then serve as the foundation with which to build a quantitative survey so the

findings can be examined with a larger sample population (Creswell, 2003). To truly understand the impacts chronic pain has on an individual's day-to-day living, I argue that it is necessary to listen to the unmediated words of those who live with it. Therefore, there is critical need to develop a better pain vocabulary that is derived from first-person accounts using their own naturally occurring language.

The findings demonstrated in the online writing workshop will serve as an initial step in exploring the communication practices and preferences of individuals with chronic pain. As a pilot study, the qualitative data stemming from the online creative writing workshop for individuals with chronic pain will attempt to shed light on the patterns and themes in the discourse of individuals with chronic pain. Their narratives will likely inform a more focused and refined survey tool. The participants' responses, juxtaposed alongside the literature regarding provider-patient interpersonal communication exchanges, will help to provide a clear line of inquiry to further explore the communication preferences among a larger and broader population.

### **Significance of Findings**

Once data has been collected and analyzed from both qualitative and quantitative measures, the findings may contribute to determining gender specific communication preferences to help sufferers disclose of their pain and assist various audiences to help them facilitate this pain communication. If individuals with chronic pain gain emotional support and therapeutic value upon communicating about their pain, then new outlets using computer mediated communication can be created to better tap into this outlet for supportive care. Insurance providers could be implicated in terms of providing coverage to alternative health strategies. Moreover, methods like pain journaling, art therapy, and creative writing workshops

focusing on chronic pain and other non-traditional outlets could gain elevated importance and shift from being labeled as “complementary” therapies to primary treatment modalities.

Even if survey respondents participating in this research deem communicating about their pain is not therapeutic, the examination of language and narratives workshop participants provided may help to deepen our understanding of the experience of living with chronic pain. The discourse analysis can provide insight into personal, hidden and guarded identities.

In addition to providing understanding on the communication preferences and styles this study hopes to shed light on the difficult process of trying to communicate pain. It endeavors to highlight the linguistic and structural constraints to communicate pain and the burden associated with revealing a pain identity. As Jairath (1999) notes, for true holistic patient-centered care, health care providers need to provide patients with the opportunity for sharing their own experience. The findings from both qualitative and quantitative methods where chronic pain sufferers will have the opportunity to speak openly and anonymously may suggest changes to the process of the patient-provider interview commonly practiced in western medicine, shifting it from a dialogue which resembles a question and answer format to a dialectic mode where patients are empowered to talk in their own words, in their own way, from differing points of view. Ultimately, this study hopes to add to our understanding of how individuals with chronic pain make meaning of their pain and how chronic pain impacts day-to-day living by hearing from sufferers directly.

### **Revealing Pain: My Personal Account**

In the following sections and throughout this manuscript I will be writing using the first person pronoun. I justify this switch from the more scholarly, third person narrative, to the first person personal pronoun, in that disclosing my own pain identity has been strategic in helping

me recruit and earn trust from my respondents and gain entree into a protected and guarded world. As a fellow chronic pain sufferer and in alignment with a social constructionist stance articulated by Lincoln and Guba, (1994), the use of first person enables me to align myself and do research *with*, not *on* my participants.

This concept of identity resonates with me as an individual and as a researcher for my interest in this topic originates from my own experience with chronic pain. While I thought I could keep this part of my identity hidden while conducting this research, I realize that my own connection to this topic will allow me to connect to my participants in a way that is sincere and empathetic. In fact, my personal experience with chronic pain is integral to building rapport with my participants. As Gadamer (1989) suggests, understanding begins with our fore-meanings, or what we know to be true without being taught-- our experiential knowledge. My own research agenda has been shaped by my own experience with pain.

Chronic pain is my lived experience; it is something I have been dealing with for 25 years. It started as mystery headaches when I was in sixth grade. The pain came on suddenly, a pressing pain behind my eyes and forehead and lasted for days. However, as real and visible as this pain was to me, no doctor could identify it. My physician said the headaches were made up to get attention; the Ear Nose and Throat physician said they were caused by stress; the neurologist said they were part of an immune disorder; the allergist said they were caused from chronic sinusitis. Eventually diagnoses of chronic respiratory and sinus infections ensued, followed by asthma and immunodeficiency. Each specialist attributed the pain differently and had their own pills to treat it yet, none provided any relief.

This constant battle with pain, with trying to diagnose it, treat it, cope with it and understand its triggers, has dominated my life. It has dictated my involvement in sports and

fashioned my strengths and skills. It has earned me the childhood nickname of “Tylenol” since I constantly was taking medicine and my friends joked I was on the 80% plan in high school as I routinely missed one day a week due to illness. The weekly medical appointments limited my involvement and excluded me from activities; the strict diet and sterile environment in which I had to live distanced me from peers and strained relationships.

Living with chronic pain has provided me with some advantages and benefits. The time spent in bed allowed me to develop a love for reading and honed the craft of observation. Involvement in testing new drugs for market consumption which required extensive pain journaling strengthened my writing skills. The time spent waiting in office rooms, for X-rays and lab test results, deepened my patience and feelings of empathy for others in the waiting room. In short, pain has shaped who I am and is something I constantly have to negotiate. It factors into my everyday functionality, impacts all of my decisions, can be an excuse, a constraint I have to overcome, and an unknown factor I have to account for in my planning.

All of these experiences will allow me to align myself with my participants as an equal. Once I disclose of my own history with pain, I hope my interest in seeking participant involvement will be perceived not as that of a researcher trying to advance scholarship, but as a fellow chronic pain sufferer looking to relate. This latter position will enable me to reach participants on a deeper level, as an insider who has ethos; it is necessary that I personally relay them as credibility is at the heart of the chronic pain experience.

Individuals with chronic pain live with a hidden disability or what Pachankis (2007) calls “a concealable stigma”. While individuals with chronic pain are usually not physically marked as different, and can pass as able-bodied, questioning our claims of suffering is common practice (Joachim & Acorn, 2000). Individuals with chronic pain must be strategic about to whom we

self-disclose and we must rely on continual impression-management to maintain this acceptance (Matthews & Harrington, 2000). However, the unrelenting nature of credibility work is straining and taxing. I have spent much time and energy trying to document the pain to legitimize it to health care professionals and receive validation. I have realized it is more helpful to talk about it with others who have similar experiences, who know how much chronic pain shapes one's identity and impacts their day-to-day behavior and relationships.

### **Social Constructivism as Conceptual Framework**

This disclosure of my chronic pain identity will affect how I am approaching this research and writing up my findings. As I am part of the world which I am studying, a social constructivist perspective acknowledges this involvement. As a researcher, I am not only exploring a world I want to analyze, but I am also placed in and constructed by that world. My admission of partiality follows feminist frameworks and allows my role as researcher/author to have more visibility (Gray, 2003). As Wendy Holloway (1989) puts it, I am “living the problem” which I am researching (p. 9). My interest in this topic spawns directly from my own lived experience with chronic pain and the research process and response from participants will be shaped by how I reveal my own chronic pain identity. In this way, I am taking Wright Mills' (1959) advice and fusing my personal and intellectual life, using both to enrich the other.

I acknowledge my own involvement and argue it is not a disqualification for conducting research. Rather, the partiality is inevitable, as all approaches are limited by a particular time and space and are motivated by desire, interest and power (Harroway, 1991). It is necessary that I am forthright in revealing my own connection to the topic. The consequence of this transparency is it starts to remove the mystique of the objective; one way of doing this is by using the personal pronoun “I” which removes the cloak of disinterested researcher and grants a sense of



responsibility, ownership and authorship of the research; (Gray, 2003). As Stuart Hall (1992) states, using a social constructivist perspective means having something at stake. For me, this research has added significance because it is a way to understand my own identity and how it has been shaped by cultural forms.

Additionally, a social constructivist approach necessitates that I have an appropriate place for myself in my research and a thorough practice of reflexivity (Gray, 2003; Johnson et al., 2004). Of Lincoln and Guba's (1985) three fundamental questions that structure research projects, they ask "what is the relation of the knower to the known?" (p. 109). This epistemological question gets at not only how we know what we know, but also asks how researchers are located as subjects within our own research. Accounting for my own position and framework is needed as it will have a profound influence in my methodology and how I interact with my participants.

The degree of conscious involvement with the other of research contrasts from the detached attitude towards subjects that scientific objectivity mandates (Lindlof & Taylor, 2011). The separation of the self from the other stems from a belief in an objective world out there that can be divided from the researchers' lives and values (Guba and Lincoln, 1994; Morrow, 1994). While positivists may be inclined to dismiss social constructivist findings due to researcher bias, I argue that my own disclosure and involvement will assist my recruitment process. As noted by Thompson (1995) positivist researchers are trained to contain emotions and distance themselves from subject entanglement; as a social constructivist researcher, I acknowledge the connection I will have with those I study (Wilde, 1992).

Moreover, the distance positivists have from their subjects precludes them from hearing from them, but favors conducting research to or on them, whereas social constructivist

researchers are viewed in partnership with participants where the aim is to develop ideas together (Lincoln & Guba, 1985). Here, there is no separation between research and practice as the researcher is the instrument (Denzin & Lincoln, 2000). The external world is constantly being interpreted by the researcher and the researcher must therefore be reflexive and examine how his/her positioning, including gender, ethnicity, socio-economic status and culture, affect his/her observations. From the very start, researchers must locate themselves and their subject of study within the specific context of research investigation and production (Gray, 2003). Instead of being seen as researcher bias, and thus a weakness, social constructivism encourages researchers to work on topics personally significant to them as the partiality provides opportunity to better participate with their subjective topics (Johnson et al., 2004). Gadamer (1989) insists the “I-Thou relation” is not only between persons, but is mediated by language and cultural form. Consciousness of one’s own partiality is an important aspect of dialogue with others.

My status as a fellow chronic pain sufferer will help me align myself with my participants and try to examine their experiences and perceptions without imposing a framework on them that may distort their ideas (Holloway & Wheeler, 2010). By exploring the insiders’ view, I will take on an emic perspective by drawing on others’ lives and accounts of their experience (Harris, 1976). By describing the world of chronic pain through the meanings and language individuals with chronic pain use to attribute their own experiences I hope to achieve emic competency. Participants are responding to me, in both my physical presence as a woman living with chronic pain and my symbolic presence as a graduate student conducting research, as much as they are responding to my research questions. Similar to my participants, I am learning to speak out from a limited and marginalized position as a woman with chronic pain. By accounting for my own subjectivity, I hope to present a clear framework for my research process.

## CHAPTER TWO

### LITERATURE REVIEW

As noted by several scholars, pain is a phenomenon that is inherently resistant to language (Maranhao & Streck, 2003; Strong et al., 2009; Birk, 2013; Main, 2014; Scarry, 1985; Jackson, 2005). Shapiro and Teasel (1997) posit that describing a personal, private and subjective experience such as pain is a difficult task. A sufferer's faculties may be comprised by the sensation of pain and one's speech and thought process may be distorted by medications used to treat pain (Birk, 2013). As Arthur Frank (1995) in his book *The Wounded Storyteller* states, chronic pain hampers the ability of the sufferer to talk about pain coherently and intelligently. Frank (1995) concludes, people in pain are "wounded not just in body, but in voice" (p. xii).

While pain exists without being voiced, it takes a public expression to give pain a reality (Waddie, 1986). In *The Body in Pain*, Elaine Scarry (1985) conveys the incommunicability of pain:

When one hears about another person's physical pain, the events happening within the interior of that person's body may seem to have the remote character of some deep subterranean fact, belonging to an invisible geography that, however portentous, has no reality because it has not yet manifested itself on the visible surface of the earth (p. 3).

The contradiction of trying to express the inexpressible sets the agenda for this literature review and research will hope to shed light on the exigency of pain communication. Exploring chronic pain from within the field of communication provides an opportunity to look at the way

pain is communicated, by whom, and the consequences of expressing pain. The theoretical framework involves the intersection of provider-patient communication interaction, gender, and disclosure. These three constructs shed light on the way pain is communicated in clinical settings; how gender differences affect the expression and treatment of chronic pain; and the repercussions of disclosing a chronic pain condition or identity. By consulting multiple perspectives and paradigms this literature review hopes to provide a more holistic portrayal of chronic pain. Given the wealth of information available, it is by no means an exhaustive look. Rather, it tailors attention by unearthing layers that shed light on the experience of living with chronic pain.

My goals for this chapter are to point out the reliance on positivism and patriarchal language influencing pain communication. I hope to identify language difficulties when trying to communicate an abstract sensation as well as address the implications ineffective pain communication has on patient outcomes and quality of life. By turning attention to creative writing techniques I aim to show how pain communication can be assisted by non-linear and metaphorical expression. This literature review sets up the framework for the argument that ritualistic means of inviting people with chronic pain to talk about their experience through using creative expressions is a viable way to study communication preferences and discourse patterns among individuals with chronic pain.

Part one provides an overview of provider-patient communication practices, including benefits of, barriers to and strategies for effective communication. Part two explores gender differences in the ways pain is expressed, validated and treated. Part three dissects the act of disclosure, including a look at language, alternatives to language, and stigma associated with the act of disclosing chronic pain. Cultural influences on pain expressions, responses and treatment

are discussed in part four, along with drawbacks associated when trying to define cultural influences. Once the intersection of gender and disclosure has been discussed, gaps in the literature and strategies to overcome them are noted in part five including a discussion on symbolic interactionism to note the influence of a clinical environment; creative techniques to encourage patient-centered, individual accounts of pain; and a feminist perspectives to offset the positivistic bias. Finally, part six provides a rationale for further research.

### **I. Provider-Patient Communication Overview**

Health care provider and patient interaction is hinged on communication (Teutsch, 2003). Although sophisticated technologies may be used to assist in diagnosing and treating a medical condition, communication is the primary tool by which physicians and patient exchange information (Street, 1991). However, this interaction can be strained because of the non-equal positions, the non-voluntary context, and the inherent exigency of the nature of pain (Ong et al., 1995). Most complaints about health care providers pertain to communication issues, not clinical competency (Tongue, Epps, & Forese, 2005). While patients value skilled diagnoses, they also want skilled communicators (DiMatteo, 1998). Given the dual tasks facing providers, provider-patient interaction can be emotionally laden and requires close cooperation (Ong et al., 1995).

The literature review of provider-patient communication compiled by Ong et al., (1995) shows patients value both cure-oriented and care-oriented behavior. The former prioritizes instrumental, cognitive, and task-focused behavior and is associated with a provider's competence; the latter values affective and socio-emotional behavior and establishes and maintains positive provider-patient relations (Ong et al., 1995). Patients often regard their doctors as one of the most important sources of psychological support (Baile et al., 2000) and their physicians' ability to show empathy is one of the most powerful ways to reduce feelings of

isolation and provide validation to their feelings and thoughts (Ha & Longnecker, 2010). While studies are inconclusive about which type of communication patients prefer (Roter, Hall & Katz, 1988), and some point out the overlap inherent in the two in that informational communication can fulfill an emotionally supportive function (Roter, Hall & Katz, 1987), successful therapeutic provider-patient relationships consist of shared perceptions and feelings regarding the nature of the problem (Ha & Longnecker, 2010). While this cursory overview shows how communication is a foundation for communication interactions, the following section examines how communication is enacted between providers and patients.

#### **A. Communication Model: Information Exchange**

In terms of analyzing provider-patient communication, several interaction analysis systems (IAS) have been developed to observe and analyze medical encounters (Ong et al., 1995). Two types of IAS are cure systems, meant to capture instrumental behavior, and care systems, meant to measure affective behavior (Bensing, 1991). In provider-patient interactions information exchange is the dominant communication model which places more attention on cure-centered exchanges where giving and seeking information is the goal than on care-centered behavior such as showing concern and providing verbal support (Ha & Longnecker, 2010; Ong et al., 1995).

For physicians, information is sought to establish the right diagnosis and treatment plan (cure-centered); for patients, information is needed to know and understand what is causing the pain (cure-centered), as well as the need to feel known and understood (care-centered) (Ong et al., 1995). Patients' personal characteristics such as levels of anxiety and education and their tendency to ask questions have been related to physicians giving diagnostic and treatment

information while patients' communicative styles such as expressing concerns and opinions have been linked to physicians using collaborative and partnership-building statements (Street, 1991). In order to fulfill both of the informational and supportive needs, providers and patients must actively engage in information giving and information seeking yet finding this balance where both parties are seen as mutual contributors is difficult (Ong et al., 1995).

A quantitative study measuring the communication content of provider-patient interaction conducted by Roter, Hall and Katz (1988) reveals physicians' contributions to the medical dialogue account for 60% of the interaction on average compared to patients' contribution of 40%. While question-asking by physicians account for 23% of the interaction, the questions are mainly close ended (yes or no answer) and occur during the patient's history intake (Roter, Hall & Katz, 1988). The opportunity for patients to ask questions is rare, with only 6% of provider-patient interaction allocated to question-asking (Roter, Hall & Katz, 1988). Female patients tend to ask more questions and receive more information from their provider than male patients (Waitzkin, 1984). Research has demonstrated that physicians often discourage their patients from asking for more information or voicing their concerns; subsequently, patients may feel disempowered and may suffer from a lack of understanding which can negatively affect their health goal achievement (DiMatteo, 1998).

Since the 1970s the health consumer movement has shifted the medical community from paternalism to individualism where patients are seen as consumers, have more involvement in the decision-making process and are more informed, even of bad news and bleak treatment prospects (Herndon & Pollick, 2002). Historically, stemming out of Talcott Parson's work in the 1950s, physician authority was uncontested and considered paramount in making decisions (Teutsch, 2003; DiMatteo, 1998). In the post-World War II era, paternalistic authority was

acceptable, especially in the medical field where medicine was perceived as a “miracle-working” profession (DiMatteo, 1998, p. 330). The ability to challenge physician authority highlighted the drive for self-determination, autonomy, and patients’ right to seek alternative care and use alternative practitioners (Haug, & Lavin, 1983). This patient-centered method stressed the care oriented system more than the cure-centered (Ong et al., 1995) and placed greater emphasis on the needs of the patient, rather than the desires and good intentions of relatives (Fentiman, 2007). With the ability to challenge authority and gain second opinions came an erosion of trust in the provider-patient relationship and the need to build trust through effective communication and by showing concern for the patient as a person (DiMatteo, 1998).

Currently, the trend in health care continues to emphasize patient-centeredness. The Institute of Medicine’s (2001) health system for the 21<sup>st</sup> century report defines patient-centered care to encompass “qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient” (p.3). Patient-centered care is fostered by good provider-patient communication so that the needs and wants of the patients are understood and addressed and patients can participate in their own care (Michie, Miles, & Weinman, 2003).

### **B. Benefits of Improved Communication Skills Between Providers and Patients**

The three main goals of current provider-patient communication are developing strong interpersonal relationships, facilitating information exchange, and including patients in decision making (Lee et al., 2002). Obtaining these goals has important implications for patient outcomes (Wright et al., 2006; Teutsch, 2003). Patients who report good communication with their providers are more likely to be satisfied with their care, better understand their problems, follow advice, and adhere to prescribed treatment and behavior change (Maguire & Pitceathly, 2002; Hall, Roter & Rand, 1981; Roter, 1983; Tongue, Epps, & Forese, 2005; Wright et al., 2003). A



positive correlation exists between sharing opinions and patient knowledge about illness and adherence to medical recommendation (Carter et al., 1982). Good communication along with the opportunity to share in the decision-making process enables patients to perceive themselves as actively involved in their healing process, increasing their self-efficacy and confidence in their outcomes (Stewart et al., 2000). Patients' distress and propensity to develop anxiety and depression are also lessened when providers use communication skills effectively (Maguire & Pitceathly, 2002).

Deficient communication between doctors and patients has been shown to negatively affect patients' perceptions of the extent the provider cares for them (Beck, Daughtridge, & Sloane, 2002); competence (Hall, Roter, & Rand, 1981); willingness to share their concerns (Schmid Mast, Hall, & Roter, 2008); and outcomes of care (Beck, Daughtridge, & Sloane, 2002). Doctors' questioning and negative talk were negatively associated with patient compliance to prescribed medical treatment whereas information-giving and positive talk were favorably associated with compliance (Roter, 1989).

Additionally, studies have shown a more patient-centered encounter pleases patients as well as providers as satisfied patients are less likely to file complaints or initiate malpractice claims (Hall, Roter & Rand, 1981; Brown et al., 1999). Providers with strong patient communication report greater job satisfaction which helps in reducing burn-out and lowering stress (Maguire & Pitceathly, 2002) and delivering higher quality of care (Dugdale, Epstein, & Pantilat, 1999).

### **C. Barriers to Effective Communication Between Providers and Patients**

While the literature attests to the importance of strong interpersonal communication skills between provider and patient, there are many barriers that impede this process. From the

provider perspective, high patient loads and burden of work, fear of litigation, and unrealistic patient expectations serve as constraints; from the patient perspective, anxiety and fear act as barriers (Fentiman, 2007). Moreover, communication skills tend to decline as medical students progress through their medical training (DiMatteo, 1998). It wasn't until the 1990s that medical schools paid more attention to ensuring necessary interpersonal communication skills were taught in undergraduate or postgraduate training (Maguire & Pitceathly, 2002; Teutsch, 2003). Communication skill classes are usually not offered in the medical curriculum until the third or fourth year to coincide with the clinical component of training (Humphris & Kaney, 2001). While third and fourth year medical students gain confidence from interacting with live patients, rather than simulated health exchanges beginning medical students have, these experiences did not increase their confidence, nor ability, of experienced medical students to engage in more complex communication such as discussing sensitive issues or breaking bad news (Kaufman, 2007).

A qualitative study reveals medical students hold a negative attitude toward learning communication skills, indicating medical students have a disdain for soft science approaches and common sense skills that are too easy and feel they are already good communicators (Rees et al., 2002). Subtle differences exist between perceptions of health care provider communication skills and gender, with female physicians more likely to demonstrate patient-centered, empathetic communication and provide more psychosocial information than male physicians (Wright et al., 2003). Other research has found that male medical students are slower at learning communication skills than females (Marteau et al., 1991).

Other constraints to effective provider-patient communication include a lack of attention given to assessing patients' psycho-social skills (Dugdale, Epstein, & Pantilat, 1999). Providers'

reluctance to inquire about the social and emotional impacts of patients' problems have been attributed to a fear that it will increase patients' distress, damage patients psychologically, take up too much time, and threaten their own emotional survival (Maguire & Pitceathly, 2002). Doctors may resist fully informing patients of dismal outlooks, especially in the case of cancer, for fear of triggering their own negative emotions (Greenwald & Nevitt, 1982). Providers may demonstrate blocking behavior, which may entail offering advice and reassurance before the main problems have been identified; dismissing distress as normal; attending to physical aspects only; and switching the topic (Maguire et al., 1996). Moreover, the physical and emotional demands of medical training have been observed to suppress empathy, emphasize technique and procedure over talk, and possibly result in disdain of patients (DiMatteo, 1998).

Time constraints may also work against providers' ability to discuss emotional and social impacts of patients' problems. The abbreviated office visit combined with physicians' inability to handle these issues negatively affects patient communication (Maguire & Pitceathly, 2002; (Dugdale, Epstein, & Pantilat, 1999). This display of avoidant behavior can cause patients not to disclose of their problems which can delay and adversely affect their recovery (Maguire & Pitceathly, 2002). Additional barriers that impede patient-centered communication are language barriers, racial and ethnic differences between the patient and provider, effects of disabilities on patients' health care experiences, and providers' cultural competency (IOM, 2001).

#### **D. Strategies for Effective Communication Between Providers and Patients**

Recommended strategies for effective communication include collaborative communication which is a two-way, reciprocal exchange of information (Ha & Longnecker, 2010; Teutsch, 2003). It positions the patient and provider as equal contributors to the health plan and takes into account the patient's situation and needs, rather than a standardized protocol

(Lee et al., 2002). Including the patient as partner requires more time, but can be beneficial in terms of patients' self-confidence, motivation and perceived health status (Kaplan, Greenfield, & War, 1989). Teutch's (2003) research on provider-patient communication highlights the need for providers to consider patient concerns, values, cultures, preferences, and gender to be an effective communicator. Teutsch (2003) also points out the therapeutic value that comes from allowing patients to vent concerns in a safe environment with a caring provider.

Recommended communication strategies to invite patients to disclose their problems and concerns include maintaining eye contact and encouraging patients to provide details, dates, key events and exact sequences in which their problems occurred as well as asking about patients' perceptions and feelings (Maguire & Pitceathly, 2002). A direct interview style with specific probes and requests for detailed information has been associated with obtaining higher quality, factual information than that associated with a more free-style approach (Cox, Hopkinson, & Rutter, 1981). Listening attentively, showing empathy, and using open-ended questions are strategies providers can employ to evidence strong communication skills (Ha & Longnecker, 2010). Other verbal behavior that is valued by patients from their providers includes empathy, reassurance and support, patient-centered questioning techniques, humor, psychosocial talk, friendliness, courtesy, explanations, summarizing and time in health education (Beck, Daughtridge & Sloane, 2002).

Many studies recommend increased emphasis on communication training in medical education (Wright et al., 2006; DiMatteo, 1998). In 1999 the Accreditation of Council for Graduate Medical Education implemented a new component of residency programs and physician certification which requires an assessment of competent communication and interpersonal skills (Teutsch, 2003; Duffy et al., 2004). According to the Communication,

Interpersonal Skills, and Professional Evaluation form (n.d.), resident physicians are evaluated for their willingness to listen to patients and families; ability to explain information and changes in care plan using clear terms; and cooperation with nursing and allied staff. While communication training can improve health care professionals' efficiency and effectiveness in communication, Teutsch (2003) points out the emphasis on training does not replace the value of showing compassion, empathy and practicing two-way communication.

To deliver patient-focused care that is culturally competent, the Office of Minority Health developed a set of Cultural Competency Curriculum Modules that train providers with cultural and linguistic competencies aimed at targeting patients with limited English proficiency (Think Cultural Health, 2011-15). Web-based courses for effective communication have been developed by the Health Resources and Services Administration (n.d.) for providers that integrate concepts of health literacy, cultural competency and limited English proficiency.

## **II. Gender**

According to Judith Lorber, who has examined the intersection of gender and health care in her book *Gender and the Social Construction of Illness* (1997), a complete analysis of health and pain must include gender. Gender not only affects pain perception, pain coping and pain reporting, but also pain-related behaviors such as use of health care and the social welfare system (Akhani et al., 2014). While studies show roughly one in four Americans live with chronic, non-cancer pain, women disproportionately experience and acknowledge their chronic pain (Hardt et al., 2008; Darnall, 2011; Wertich, 2014). Some chronic pain conditions are women-specific (vulvodynia, dyspareunia, pelvic pain) while other conditions are more prevalent in women (fibromyalgia, irritable bowel disorder, migraine, arthritic conditions, complex regional pain

syndrome) (Darnall, 2011). Aggregating the results reveals women are more likely to acquire a chronic pain condition in their lifetime (Darnall, 2014).

Additionally, research has shown women report more pain, a higher severity of pain and a longer duration of it (Akhani et al., 2014; Silver, 2004; Unruh, 1996). “Women seem to have lower pain thresholds, have a greater ability to discriminate painful sensations and report higher pain ratings on pain assessment scales” (McCool, Smith & Aberg, 2004, p. 478). Musculoskeletal symptoms are more common among women than men and women’s pain is more likely to be classified as medically unexplained disorders and emotional than men’s (Werner, Steihaug & Malterud, 2003). The differences in chronic pain incidence rates among men and women invite a further look at how gender influences the way pain is expressed, confirmed, and treated.

#### **A. Biological Differences to Pain**

Research conducted by Bradbury (2003) indicates that male and female brains process pain differently. According to PET (positron emission tomography) scans women experience pain in the limbic, or emotional, area of the brain whereas men experience pain in the frontal cortex, or intellectual processing center (Paulson et al., 1998; Naliboff et al., 2003). The different locations in which pain is received and processed could explain the tendency for women to describe pain with more emotion while men describe it more factually (Paulson et al., 1998).

Furthermore, hormones play a role in how pain is experienced. Medical studies examining the effects of reproductive hormones and pain show a link between estrogen and inflammation and pain (Dao, Knight, & Ton-That, 1998). Specifically, estrogen levels can inflate the experience of pain, causing women to sense pain sooner and reach their maximum pain threshold sooner during and around menstruation (Fillingim et al., 2009). Consequently, researchers are studying the correlation between a decrease in estrogen levels and an increase in

the vulnerability to pain (Fillingim et al., 2009). Additional findings suggest women are biologically more sensitive to pain than men (Berkley, 1997; Fillingim & Maixner, 1995).

In response to pain, women utilize a variety of coping techniques such as problem-solving, emotion-focused coping, relaxation, distraction, social support and expressions of feelings whereas men rely on direct action, problem-focused coping, denial, and tension-reducing activities (Unruh, 1996). Moreover, Werner, Isaksen and Malterud (2004) concede women must learn to cope with the skepticism and distrust they report they are met with when disclosing of their pain.

### **B. Women's Efforts to Communicate Pain**

The question of whether women experience and express pain differently than males is a relatively recent one and may have been triggered by the 1993 legislation requiring the inclusion of women in National Institute of Health sponsored research (National Institutes of Health Revitalization Act of 1993). Research exploring accounts of women's illness stories reveal feelings of shame and issues of self-worth (Werner, Isaksen & Malterud, 2004). In particular, women are perceived to complain more about their pain than men (Elliott et. al., 1999; Silver, 2004). This "complaining" can position women in an inferior light, making them feel ashamed and shy when talking about their illness (Werner, Isaksen & Malterud, 2004).

An alternate look at illness accounts perceived as complaints is found in Kugelman's (1999) research conducted on working class men and women whereby illness narratives resembled legal proceedings in that pain sufferers were filing a complaint in hopes of rectifying a wrong (Kugelman, 1999). Complaints in this research were perceived as bestowing a sense of agency on the sufferers as they were doing more than dispensing information, but calling for action (Kugelman, 1999). In Kugelman's (1999) study, men were more likely to interpret their

pain as a form of grievance against someone or because of some injury, which contrasts from Unruh's study suggesting women are more likely to passively accept their pain as part of life (Unruh, 1996).

Research suggests that women who try to communicate their pain with their doctor may be regarded as hypochondriacs or their pain may be dismissed by doctors as symptoms of psychosis or stress (Ford, 1995). Women often struggle for the maintenance of self-esteem and dignity at the risk of being shamed and disempowered, both as women and as patients (Werner & Malterud, 2003). Chronic pain conditions like fibromyalgia have been described as "new psychiatric disorders" and modern forms of "hysterical epidemics" (Werner, Isaksen & Malterud, 2004, p. 1037). Historically, medical literature in the 19th century widely discusses the diagnosis of hysteria being exclusively linked to women (Maines, 1988). Women were therefore seen as being sickly, weak and needing to be taken care of by men (Johannisson, 2001). Werner, Isaksen and Malterud (2004) report that women are frequently questioned and judged either to be not ill, suffering from an imaginary illness, or worthy of receiving a psychiatric label. The uncertainty of symptom presentation casts much chronic pain into the territory of mental illness (Jackson, 2005) and hysteria (Shapiro & Teasell, 1997).

Individuals with chronic pain experience failure when their accounts of pain are disbelieved (Newton et al., 2013). Norma Ware (1992) calls this delegitimation and explains it as "the experience of having one's perceptions of an illness systematically disconfirmed" (p. 347). When faced with disbelief over medically unexplained symptoms or contested illness, Johansson et al., (1996) discovered that women may employ several strategies to garner the attention of medical providers including somatizing, which entails presenting bodily symptoms and explanations that would seem acceptable to the doctor; or diffusing their straightforward



demands by couching their own knowledge by referring to other authorities such as “My neighbor, who is a doctor, said...” (p. 500). Other strategies female patients employ to attract their medical provider’s attention included appealing to flattery by acknowledging the doctor’s supremacy; presenting themselves as ignorant; and crying, begging and pleading (Johansson et al., 1996).

Werner and Malterud’s (2003) research illustrates the amount of work female patients conduct in order to be believed, understood and taken seriously by their doctor, concluding that more emphasis is put on demonstrating their legitimacy as credible patients than on discussing treatment and care for their illness. Johansson et al., (1996) determined that the efforts women exert to gain credibility highlight the asymmetrical doctor-patient relationship where the doctor’s role is characterized by high status and the need to correct and control the patient, and the patient has little agency and low respect. Werner and Malterud, (2003) advise that women must take care to reflect “a subtle bodily and gender balance to not appear too strong or too weak, too healthy or too ill, or too smart or too disarranged” (p. 1037).

Moreover, Nguyen et al., (2013) found that 30% of women in their 12, 834 sample population believed doctors held stigmatizing opinions that individuals with chronic pain exaggerate their pain level. Despite this perceived negative stereotyping, women still sought medical care, possibly because “their pain and discomfort were too great to bear without speaking to a physician” (Nguyen et al., 2013, p. 1466). When individuals with chronic pain were tasked with describing a past pain event Strong et al.’s (2009) findings show that women used more words and more graphic language than men and focused on the sensory aspects of their pain event while men, on the other hand, used fewer words and focused more on events and emotions.

### **C. Women's Efforts to Validate Their Pain**

Of the more than 100 millions of Americans who have chronic illness or pain, (Institute of Medicine, 2011) less than one percent use a cane, walker or wheelchair which makes their disability visible (Sisk, 2007). Without the visible disability, individuals with chronic pain may be able to “pass” as able-bodied (Joachim & Acorn, 2000; Pachankis, 2007). The hidden interiority of pain calls for sufferers to have to work to validate that pain exists in their unmarked bodies (Werner & Malterud, 2003). In the absence of any external signs, Birk (2013) argues that individuals with chronic pain are integrated into mainstream society and don't have to fight for integration like other disabled populations. However, their ability to pass is also one of their greatest obstacles because their ability to conceal necessitates they engage in constant pain performance to gain validation and legitimation (Jackson, 2005; Ware, 1992; Birk, 2013).

Credibility is at the heart of chronic pain as pain is only claimable through self-reports and pain behavior (Herr et al., 2011; Birk, 2013). It is well-documented that individuals in pain struggle to retain some semblance of credibility and control when medical providers doubt the veracity of their complaints (Kleinman, 1988, 1992; Skuladottir & Halldorsdottir, 2008; Werner et al., 2004). When a person's integrity is challenged she can become “invalidated as knower” and her voice can be repressed (Wendell, 2006, p. 254).

The efforts women exert to convey private and invisible phenomena to a public audience can be regarded as a performance (Werner & Malterud, 2003). Similar to Judith Butler's (1993) contention that gender identity is a set of performative practices, Werner and Malterud (2003) posit chronic pain identity as a performance. Applying Butler's (2003) view of performance to chronic pain shows that chronic pain is not a natural part of oneself, but this identity is established through repeated performances. Multiple studies attest to individuals with chronic

pain endeavoring to achieve a sick role and thus legitimizing their chronic illness (Eccleston et al., 1997; Kugelman, 1999; Ware, 1992; Asbring & Naravanen, 2002). The acting out of pain through discursive practice helps to construct one's identity (Butler, 2003). Butler claims:

performativity is not a singular 'act', for it is always a reiteration of a norm or set of norms, and to the extent that it acquires an act-like status in the present, it conceals or dissimulates the conventions of which it is a repetition...within speech act theory, a performative is that discursive practice that enacts or produces that which it names" (2003, p. 12-13).

Yet Werner and Malterud (2003) assert the very acting out of the pain behavior can discredit the performer as they may be accused of exaggeration or over-reacting. Birk (2013) calls it a catch-22 for individuals with chronic pain: without the physical signal of pain, physicians have no external reality of which to verify the pain, but the acting out of pain diminishes the credibility of the individual. As Elaine Scarry (1985) states, "Thus pain comes unsharably into our midst as at once that which cannot be denied and that which cannot be confirmed" (p. 4).

Additionally, the performativity of pain is contradictory in nature as in order to alleviate pain individuals first must reproduce it (Birk, 2013). As Jean Jackson (2005) argues in her article *Stigma, liminality, and chronic pain—mind-body borderlands*, the cause of stigma for individuals with chronic pain, or the deviant behavior, is inappropriate pain behavior. Jackson (2005) continues by claiming "Pain is doubly paradoxical: It is a quintessentially private experience that depends on social action to make it real to others, yet that very same action can also arouse suspicions about its reality" (p. 342). Pain performances can leave the performer

feeling like a discredited actor; isolation, alienation and resistance to treatment may ensue (Birk, 2013).

A poor pain performance or failing one's credibility work has negative implications for the patient's condition (Wendell, 2006). Hilbert (1984) says the inability to document what their bodies experience and an official announcement by a medical professional stating they should not be in pain can lead to social isolation. If the patient does not gain validation by the medical professional, the patient can feel invalidated and undermined (Wendell, 2006). What may appear to be good news like when a doctor finds 'nothing wrong' can equate to huge disappointment by the sufferer (Hilbert, 1984). Unexplained disorders are often met with negative medical encounters, resulting in women feeling misunderstood, doubted, rejected, ignored, belittled, blamed and assigned psychological explanations (Werner & Malterud, 2003). To uphold their self-respect women may mystify their symptoms, adopt a self-image of being an anomaly, martyrize themselves by conveying the image of the silent-sufferer, refrain from complaining, or condemn their physicians as ignorant (Johansson et al., 1996).

#### **D. Women's Efforts to Gain Treatment for Their Pain**

In terms of treating chronic pain, women are more likely than men to seek medical attention for a health problem, but this initiative does not necessarily translate to better care (Unruh, 1996). There is a growing body of literature that indicates women are more likely than men to be undertreated or inappropriately diagnosed and treated for their pain based on the presumption women can handle more pain, or alternately, that women are imagining pain when none exists (Hoffmann & Tarzian, 2001; Calderone, 1990; Unruh, 1996). Historically, women have been portrayed in the medical literature as hysterical and oversensitive (Sherwin, 1992) Females with chronic pain are more likely to be diagnosed with histrionic disorder, excessive

emotionality and attention-seeking behavior (Fishbain et al., 1986). Although women more often report pain to a health care provider, they are more likely to have their pain reports discounted as emotional rather than objective statements (Fishbain et al., 1986) or attributed to “psychogenic” properties and therefore, not real (Hoffman & Tarzian, 2001, p. 21).

Further, women’s pain reports are taken less seriously and women receive less aggressive treatment for their pain than their male counterparts (Hoffmann & Tarzian, 2001). Upon initial encounters with their physicians, women are less likely than men to be referred to a specialty pain clinic (Weir et al., 1996). One study showed that women have an increased likelihood to be given sedatives for their pain while men have an increased likelihood to be given pain medication (Calderone, 1990). While opioid drugs are commonly prescribed to treat chronic pain, the Center for Disease Control and Prevention reports they are disproportionately prescribed and are given in higher doses to women than to men (CDC, 2013). This treatment tendency may be explained by psychosocial factors such as society’s willingness to tolerate and care for sensitive women who state their pain, but forbid men the same expression (Silver, 2004).

Additionally, patient characteristics and behaviors such as negative affect, psychological distress, grimacing or bracing observed by the physician in an office visit may influence the likelihood that the physician will prescribe an opioid (Darnell, 2011). Minus the physical manifestations of pain, individuals with chronic pain are often accused of not looking the part and play into the cultural misperception that says you’re not sick unless you look sick (Fennell, 2001). Cultural norms and socialization practices that dictate women need to try to look good even when going to the doctor can have sway on physicians’ perception that the patient looks too good to be in pain (Ware, 1992). Hadjistavropoulos, McMurty and Craig (1996) studied the way physicians distinguished between their “attractive” and “unattractive” patients and concluded

that attractive female patients were perceived as experiencing less pain than unattractive female patients. This study's findings perpetuate a "healthy is beautiful" stereotype among women (Hadjistavropoulos, McMurty & Craig, 1996).

Filligim et al., (2009) draw attention to the lack of research funds devoted specifically to women's pain and acknowledge existing research on gender differences and pain is deficient because it favors clinical studies and uses quantitative methods which focus on amounts of pain reported or analgesia used by the sexes. They recommend that qualitative studies may provide the most compelling rationale for the development of pain treatments specific for women (Filligim et al., 2009).

### **III. Disclosing Chronic Pain**

Pain's invisible and inaudible nature places onus on sufferers to communicate and validate their pain (Main, 2014). To counter the challenges to their credibility, individuals with chronic pain must rely on continual impression management and strategic self-disclosure (Matthews & Harrington, 2000). Disclosing of chronic pain is a mixed bag of outcomes; it can bring about a sense of community when a sufferer identifies as having chronic pain and joins the more than 100 million other Americans who suffer from it (IOM, 2011), yet it is also ripe with risks of stigmatization and marginalization (Jackson, 2005; Holloway, Sofaer-Bennett, & Walker, 2007). The following section will break down the concepts of language needed to facilitate the disclosure and the risks of self-disclosing.

#### **A. Language of Pain**

In Western societies the culture and language of illness, pain, and medical knowledge comes from science and the positivistic model of disease (Morris, 1998). Positivism, as developed by Auguste Comte (1798-1857), is a philosophy of science that contends that the only

authentic knowledge is scientific knowledge which comes from positive affirmation of theories using the scientific method (Dogan, 2013). Positivist researchers are urged to seek universal laws which can then be applied via observation, experiment and comparison, irrespective of time and space (Keat, 1979). Beginning with John Locke's (1690) idea that meanings are fixed and words have distinct meanings that are static, positivism values consistency and precision. Nastasia and Rakow (2010) claim positivists believe that with a stable and fixed underlying structure, language represents and maps onto external, objective reality. Within this perspective, language simply reflects experience; it is transparent and mimetic in function (Quinter et al., 2003).

With this understanding of language, positivists have come up with a fixed definition of chronic pain to be ongoing or recurrent pain which lasts beyond the usual course of acute illness or injury or more than three to six months and which adversely affects the individual's well-being (American Chronic Pain Association, 2015). As an agreed upon convention, pain has the same symptoms and outcomes in any social situation and pain is understood as a deviation from the normal biological functioning (Mishler, 1981 in Lorber, 1997).

This definition of chronic pain exemplifies the idea that language is a transparent tool to represent a pre-existing reality. Yet Saussure (1986) claimed language is only arbitrarily connected to the external world. Dobie (2012) adds that language does not reflect, but constitutes our world and structures our experience. In Saussure's (1986) semiotics, meaning, and by extension cultural convention, is grounded in the difference between signifiers and signifieds. The value of delineating difference is in understanding how words gain meaning through their relationships with other words. Meanings are imposed on and read into these signifiers. Problems exist when a universal meaning is applied to a word as it denies cultural interpretations and variations. In a clinical setting, patients' self-reports of *pain* are interpreted within the embedded

meanings of scientific-medical discourse and presented as a value-neutral discourse having no social or political implications (Price & Cheek, 1996).

Price and Cheek (1996) point out a problem with this approach to defining pain when they identify the “the politics of sameness” which is promoted by the scientific-medical discourse (p. 901). When sufferers communicate their pain using pre-existing language their words are limited as they are not a function of the speaker, but the product of social production and of pre-existing cultural conventions (Katz, 1976; Price & Cheek, 1996). The invisible nature of chronic pain as a disability frustrates the straightforward, organic etiology language of medicine (Morris, 1998). Price and Cheek (1996) suggest that what counts as pain, who determines when someone is in pain, and how a patient expresses pain are discursive constructions. Different meanings may be interpreted from the same “reality” and various social and political implications negate the ability of health care providers to practice “sameness” in the delivery of care across facilities and persons (Price & Cheek, 1996, p. 902).

Another problem associated with a fixed nature of language is pointed out by Rice and Waugh (1989) who claim that we tend to become accustomed to the world our language system has produced, thinking it is the correct way to view the world. Quinter et al. (2003) warn that we live in a world that is constructed by language, rather than viewed through language. As patients’ self-reports of pain are the first step in pain management (Kim et al., 2012), the inability to identify difference in self-reports of chronic pain can render the sign *chronic pain* useless and lacking clinical utility in medical diagnoses as it refutes the view that the experience and management of pain mean different things to different people (Quinter et al., 2003).

What is needed is a larger framework which acknowledges there is more than one possibility and interpretation of reality and patients’ self-reports may be influenced by social,

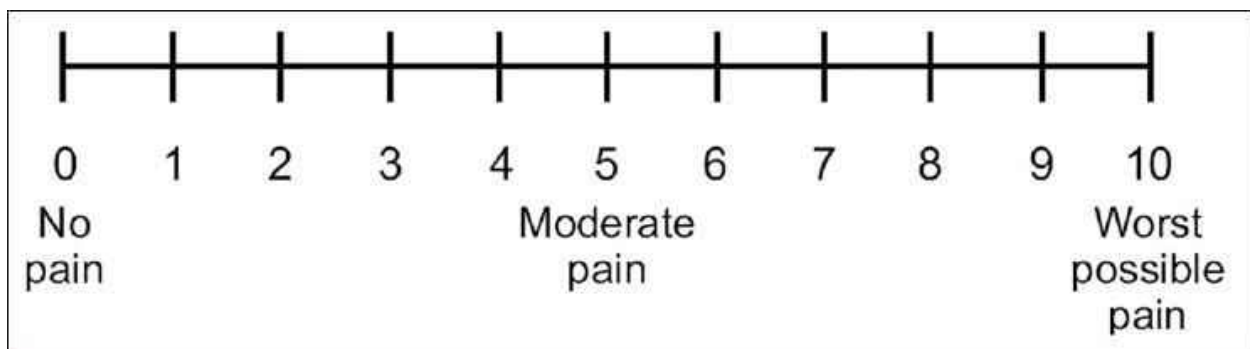


political, cultural layers. I agree with Price and Cheek (1996) who claim the best way to understand chronic pain is to allow patients the space to speak. The opportunity for patients not only gives them a voice, but highlights the variation in expressions and shows how meaning varies from individual to individual. Additionally, inviting first-person patient perspectives shifts the approach of pain assessment from a task to an opportunity for deep interaction.

### **B. Language Alternatives: Quantifying Pain**

To aid in clinicians' assessment of pain, attention has turned to objectively quantify pain behavior (Keefe & Hill, 1985). The concept of pain behavior has served as a heuristic function (Turk & Flor, 1987) and various pain scales have evolved as technology has grown more sophisticated and patients have become more culturally and linguistically diverse to methodologically assess pain behaviors (National Initiative on Pain Control, n.d.). The importance of assigning a measurement to pain is that according to Cork et al., (2003) patients obtain a sense of control over their condition and gain positive effects on their coping abilities.

The numeric rating pain scale was developed to numerically convey pain with 1 representing little pain and 10 representing severe pain (McCaffery et al., 1989).



**Figure 1. Numeric Rating Scale**

There has been limited value with pain scales because they are reported to oversimplify the pain experience and understate the difficulty in expressing the subjective and multidimensional nature of pain (Wood, 2004). One person's rating of an 8 may equate to another person's 3, leaving little clinical utility in the tool (Price & Cheek, 1996). Turk and Flor (1987) conclude that failing to take into account psychosocial, psychophysiological, and medical-physical factors may present an inadequate understanding of the patient and result in appropriate treatment interventions.

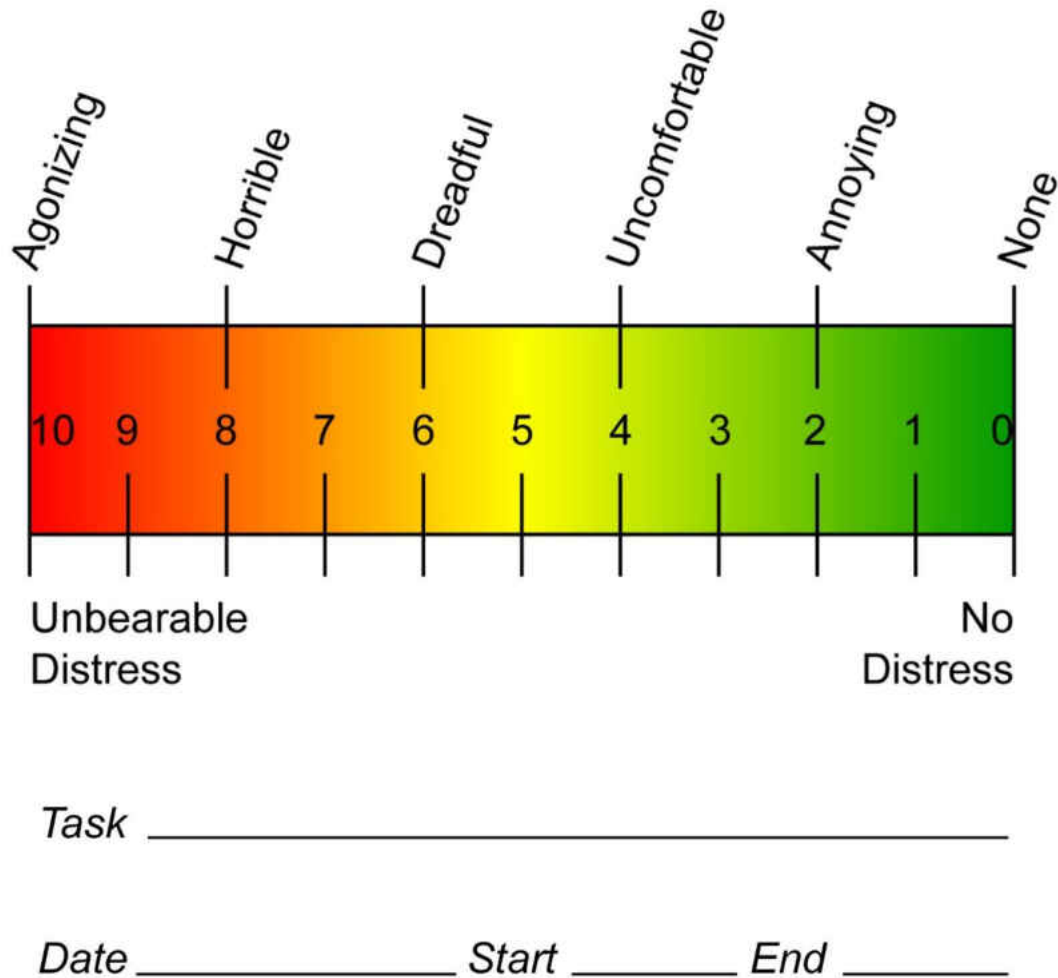
To cater to pediatric patients as well as accommodate cross-cultural patients, Visual Analog Scales (VAS) were developed which depict facial expressions associated with increasing levels of pain.



**Figure 2. Wong-Baker FACES Pain Rating Scale**

In addition to the pictogram, a hybrid strategy which employs both numbers and words has been used to describe pain. Sriwatanakul, Kelvie and Lasagna (1982) examined the descriptive words patients seeking analgesia use to measure their pain intensity, pain relief and global ratings of analgesics using a visual analog scale. Results showed a high degree of variation; meaning may change for different individuals and unequal differences exist between

descriptive terms that are commonly considered equidistant on an ordinal scale (Sriwatanakul, Kelvie, & Lasagna, 1982). A combination of a visual scale along with writing down descriptive words is recommended by the authors (see Figure 3) however, they recommend exercising caution as the success of any scale is contingent upon painstaking explanation by the health care provider and cooperation by the patient (Sriwatanakul, Kelvie, & Lasagna, 1982).



**Figure 3. Visual Analog Scale**

Many clinicians have argued against the use of pain scales, claiming pain scores: indicate how much action patients want to be taken more than a description of their pain (Rosen, 2010); do not predict the likelihood of patients to develop disease (Wong et al., 2014); and specific to

the VAS, are time-consuming to implement (Cork et al., 2003). Coniam and Mendham (2005) list multiple disadvantages of using pain scales including they are unable to detect subtle differences; responses can vary among patients and in the same patient at different times; are not suitable for research because they are semi-qualitative; and when trying to examine the effectiveness of an intervention, the patient has to remember what the pain was like before. Further carefulness is advised by Price and Cheek (1996) who warn that attention on scales places the focus on pain measurement, rather than on patients and their accounts.

With few objective measures of pain besides patients' self-reports Borsook (2012) points out that providers rely on patients to signal they are in pain (Borsook, 2012). Gevirtz (2012) argues that physicians have to become detectives and try to identify fakery among the patients who are categorized as "seekers" and inflate their pain scale number in order to receive prescription drugs. Physicians are tasked with assessing patients for the risk of aberrant drug behavior or developing an addiction to the drug; understanding the street value of the prescribed medications; discussing noncompliance with their patients; and recognizing the tendency for patients to exaggerate pain reports (Passik & Kirsh, 2004).

### **C. Risks of Disclosing Chronic Pain**

Although the invisible nature of pain does not automatically elicit feelings of disgust or revulsion, most sufferers of chronic pain report feeling marked as different (Jackson, 2005). Kleinman (1988) claims the nature of chronic pain as a lifelong, concealable illness, indiscriminate of age that is associated with a significant burden in terms of symptoms and treatment situates individuals at risk for stigmatization. Stigma is defined as social devaluation of an individual as abnormal and has been identified as an important construct in the outcome of chronic health conditions (Goffman, 1963). Individuals with chronic pain who suffer from

persistent physical and emotional effects of illness and treatment are stigmatized by society and dehumanized by the medical establishment (Holloway, Sofaer-Bennett, & Walker, 2007; Kleinman, 1988, 1992).

In a recent study examining the prevalence of stigmatization in chronic pain patients, Hegarty and Wall (2014) claim “The internalized cognitive, emotional and behavioral impact of others’ negative attitudes on a person who possesses a devalued characteristic is a real clinical reality” (p.2). Anticipated stigmatization can undermine an individual’s self-esteem and quality of life (Hegarty & Wall, 2014). When interacting with medical providers women contend they are frequently met with skepticism and rejection as well as being ignored and misunderstood (Garro, 1992; Raymond & Brown, 2000; Ostlund, Cedersun, Alexanderson & Hensing, 2001). Moreover, many researchers have found that women are stigmatized, belittled and blamed for their condition and often it is dismissed as psychological in nature, as noted earlier (Asbring & Narvanen, 2001; Ford, 1995; Werner, Isaksen & Malterud, 2004).

#### **D. Disclosing of Chronic Pain in the Workplace**

When it comes to disclosing of chronic pain in the workplace research suggests employees with chronic pain are at risk for unfair treatment (Overland, 2013). Workplace challenges which may deter individuals with chronic pain from disclosing have been identified as activity interference, negative self-perceptions, interpersonal challenges and inflexibility of work (Tveito et al., 2010).

People with chronic pain conditions are well represented in the areas of those that receive social support due to their inability to work, both by receiving wage compensation as well as early retirement benefits (Waddell, 2004). Governments have explored options to reduce costs by reducing benefit levels, increasing the medical threshold for benefit qualification, restricting

access to early retirement, introducing rehabilitation and re-employment programs for disabled people and reviewing the claims of those who remain on benefits yet there is a common attitude that regards the recipients of these benefits to be working the system and shirking their responsibilities (Watson & Patel, 2013). Fishbain et al (1995) report that disputes commonly arise over the degree of recovery, the level of expected function or incapacity, and expectations for contributions once the individual returns to work.

Moreover, there is a perception that chronic pain patients are benefitting from secondary gains, which refers to the financial and emotional rewards received as well as the relief from responsibilities as a result of their condition (Watson and Pattel, 2013). Data on secondary gain coming from the Workman's Compensation systems in North America show a correlation that an increase in wage compensation for an injury suffered on the job is linked to a slower return to work (Watson and Pattel, 2013). The evidence highlights the relationship between generous financial compensation and longer work absences. While this type of data supports the stigma held against those who are perceived to be benefitting from the system, it is important to point out this evidence is for employees who were injured on the job, primarily in blue-collar jobs.

A recent article in the *New York Times* suggests individuals with chronic pain are discouraged from disclosing for fear of being perceived as lazy, incompetent, not a team player or receiving favored status and unequal work expectations (Bouton, 2013). The American Disability Act (1990) does not require disclosure of a medical condition during a job interview or application. Common advice circulated on chronic illness blogs is not to disclose until the foot is in the door or unless symptoms affect one's performance (Joffe, 2009; Safani, 2012).

Employers may have fears when hiring individuals with chronic pain including: the fear of having to spend a lot of money on adaptations; a concern that work might aggravate the health

problem; lawsuits; or perception that if they make changes in the workplace for one employee they have created a precedence for future changes for other employees (Gifford, 2013).

Employers have been charged with not understanding persistent pain conditions, inability to comprehend why employees do not get better quickly, and uncertainty of how to support the employee to return to work (Gifford, 2013).

### **E. Disclosing of Chronic Pain to Peers**

In terms of communicating with peers individuals with chronic pain often fall into a pattern of interpersonal communication that may be more harmful than helpful. Dr. Julie Silver (2004) notes the disastrous impacts that articulating pain can have between chronic pain sufferers and their loved ones in her book, *Chronic Pain and the Family*. For example, moaning and groaning by chronic pain patients in response to pain does little to alleviate their physical condition, but it may elicit a caretaker to respond in either an overly considerate manner or overly hostile way (Silver, 2004). Both responses tend to negatively affect the sufferer and the relationship with the caretaker. The overly caring response only reinforces the disability and may foster more pain behavior. On the contrary, the antagonistic response from a caretaker can impose feelings of guilt and anger for the sufferer. In either situation, the relationship between the patient and sufferer is stressed (Silver, 2004).

Socially, individuals with chronic pain report difficulty in disclosing of their chronic condition to romantic partners (Fortenbury, 2013). According to Reis and Shaver's (1988) interpersonal process model of intimacy, intimacy is cultivated when one person's self-disclosure is met with an empathetic and validating response from the partner. Verbal communication about one's thoughts and feelings about pain are strategies to disclose emotion, elicit emotional support and build intimacy (Cano & Williams, 2010). Yet this emotional disclosure can be a "deal-

breaker” for individuals with chronic pain; the sufferer may fear rejection while the partner may fear being a caregiver (Fortenbury, 2013, sec. 3). Without the physical symptoms, Sisk (2007) acknowledges some individuals face doubt from friends and family who don’t believe them and scrutiny from bosses who perceive them taking too many sick days.

## **F. Impacts from Disclosure of Chronic Pain**

### **1. Familial Relationships**

It has been suggested that the family is the most important context within which illness occurs and health professionals recognize the extent family has in setting the pace for how it is treated and resolved (Rowat, 1985; Cogswell & Weir, 1964). Poole et al. (2004) discuss the way the symbolic-interpretive perspective offers a framework which expands the focus away from the chronic pain individual as the only subject, but extends to examine the social and behavioral dynamics of the group where the individual works, plays and lives.

According to Ballus-Creus et al. (2013) an individual’s response to chronic pain depends upon factors such as social networks and interpersonal relationships which may be supportive or obstructive. For example, Falvo (2014) points out the extent that families foster independence or dependence, acceptance or rejection, encourage or sabotage compliance with treatment recommendations has substantial effects on an individual’s functional capacity. Keefe, Gil, and Rose (1986) conclude that chronic pain impacts individuals’ environment and causes significant changes in their life and family life. As Poole et al. (2004) describe group cohesiveness depends on its ability to develop a coherent identity and vision. Conflict or fragmentation may result if the family’s vision is to eradicate pain or cure the chronic pain condition while the chronic pain sufferer may envision more familial support and empathy. Families may strive to be a “normal”



family again and feelings of anger, resentment, or disappointment may emerge when the chronic pain interferes with their expectations (Falvo, 2014, p. 23).

## **2. Marital and Parental Relationships**

A systematic review of the literature by Turk et al. (1987) and Flor et al. (1987) shows that families with a parent with chronic pain show more dysfunction than healthy families. Snelling (1994) found higher reports of tension, marital conflict and feelings of anger, resentment and despondency in families where one parent had chronic pain. Burns et al. (2013) report that spouse criticism can elevate pain intensity and negative marital interactions can inhibit the sufferer's adjustment to chronic pain. Creamins-Smith et al. (2003) acknowledge the difficulty in assessing partner's pain and both underestimations, which can lead to feelings of devaluation, and overestimations, which can lead to over-protectiveness, are associated with poor outcomes. Cano et al (2015) discuss how a partner's negative thoughts and beliefs about their partner's pain can influence how they respond to pain.

Lewandowski et al., (2007) document how chronic pain constricts family life; as communications, activities and interactions focus on pain and illness, family members may view the parent with chronic pain as having less power and status. Research conducted by Fagan (2003) illustrates how parents afflicted by chronic pain face large obstacles in their day-to-day parenting task as pain can interfere with a parent's ability to care for the child and limit their presence in the child's activities. Fagan's (2003) research shows that some children of chronic pain parents assume more household responsibility and chronic pain parents have inappropriate expectations of their children. A reverse in parent-child roles may result where children may be at risk for taking on roles for which they are not emotionally or developmentally prepared (Fagan, 2003).

As awareness of the importance of the family in the chronic pain experience expands, Rowat (1985) argues that including data relating to the family becomes necessary. This argument is reinforced by Roy (1984) who says “Without the benefit of a careful family assessment the clinical picture of the pain patient has to be considered incomplete” (p. 32). Yet Payne and Norfleet (1996) have criticized the slowness in which physicians acknowledge the significance of the family when one of its members has chronic pain.

### **3. Undisclosed Chronic Pain**

Detrimental effects to an individual’s sense of efficacy have been associated with individuals who do not talk about the experience of chronic pain (Umberger et al., 2013). Individuals with chronic pain who self-report high pain levels and lower psychological well-being have been associated with the practice of self-concealment and the tendency to hide aspects of one’s chronic pain condition (Uysal & Lu, 2011). Kolber (2007) explains pain is private on two accounts: descriptive, in that no one else can directly experience one’s pain; and normative in that individuals with chronic pain are encouraged to not feel forced to reveal information about what they are feeling; therefore individuals in pain have interests in keeping private when they are in pain, how much pain they feel, pain triggers, and pain sensitivity. Keeping pain private may protect against unwanted inquiries into subjective experiences, but it can lead to feelings of isolation (Becker, 2013).

Furthermore, the field of health communication adopts a strength based theoretical perspective which focuses on emphasizing abilities and potential as a means to foster confidence in goal attainment (West, Usher & Foster, 2011; Early & GlenMaye, 2000). The act of talking about pain emphasizes weakness and deficit in the sufferer and may evoke negative reactions in others (Jackson, 2005).

The combination of risks and stigma question the value of disclosing chronic pain and work to further disempower and silence many individuals from speaking up or advocating for their treatment, despite marks of privilege such as high levels of education and middle-class socio-economic status (Ellingson, 2004). Recent research exploring the benefits of emotional disclosure for chronic pain has shown modest benefits overall, with increased benefits for certain conditions like fibromyalgia however researchers point out further study is needed to be conducted outside of randomized control trials with a different location and method of disclosure selected (Lumley, Sklar & Carty, 2012). Although much needs to be done to advance our knowledge of the experience of chronic pain, I argue that one way is to conduct research outside of clinical settings, using social constructivist approaches that invite participation and encourage first hand testimonies and experiences.

#### **IV. Culture Differences**

When discussing internal experiences, such as the sensation of chronic pain, Birke (1998) insists that we need to examine cultural influences. Pain perceptions and behaviors are influenced by the sociocultural context of the individuals experiencing pain (Bates, 1987). Whether we have a word for pain will not just depend on whether we have ever felt pain; it will depend on the cultural resources of language. Zborowski (1952) concluded that each culture has its own language of distress when experiencing pain.

Although Raymond Williams (1961) indicates culture is one of the most complicated words in the English language, he conceives of culture as a particular and distinctive way of life of a specific group of people, including their implicit and explicit values and emphasizes the connection between culture, meaning and communication. In a social constructivist paradigm culture is connected with the role of shared meanings and social practices and enables us to make

sense of things. As Durkheim explained (1938) collective representations are social in origin, and refer to social norms and values that are expressed in behavior, rituals, institutions and religious beliefs.

Looking at pain as a social phenomenon examines the influence of society and culture. The patterns of production, consumption, identity formation, regulation and representation are what du Gay et al. (1997) refer to as a circuit of culture. By using the Sony Walkman as a case study, du Gay et al. (1997) examine how culture is a manufactured product; meaning is constructed through cultural practices and not found in objects themselves. Moreover, meaning is conveyed by using language that we already know based on what is familiar or analogous to us. In this way, meaning can be mapped as one meaning can be traced back to a previous one, so a new invention like a Walkman may be described by previous terminology like stereo-headphone-cassette player (du Gay, 1997). Applying this notion of culturally constructed meaning to pain sheds light on the culturally dependent construction of pain. Pain is not a physical object that one can touch, see, or hear, nor is meaning found in pain. It is people who attach meaning to the experience of pain and interpret the sensation of it.

Questions such as which meanings are shared within a society, who produced those meanings, how are they shared, what counter-meanings are circulating and what meanings are contested highlight the need to understand how meaning is actually produced in a given culture. These questions direct attention to the power of language, the process of communication and the medium in which meaning is constructed. The following discussion explores cultural perceptions of expressing pain, focusing on ethnic groups that are largely represented in the U.S. population and therefore serve as potential respondents in my study.

## **Cultural Influences on Pain Communication**

Talking about personal and private experiences such as pain may violate cultural norms, social etiquette and add frustration to the communication process (Cross et al., 1989). Since chronic pain does not fit into notions about acute pain which goes away, Hilbert (1984) argues those who experience chronic pain “fall out of culture” (qtd. in Jackson, 2005, p.340). C.S. Lewis, in his book “The Problem of Pain” (1940) claims a universal human belief is that bad men ought to suffer and acknowledges a belief that pain is God’s vengeance upon sin. The implication is that pain is caused by sin but Lewis later makes a distinction that while one person’s sin may tempt and infect others, one person’s pain is sterile; “suffering naturally produces in the spectators no bad effect, but a good one--pity” (p. 66). This view that equates talking about pain with pity may cause some to remain silent as Jackson (2005) summarizes an American cultural norm that dictates men who talk about their pain are seen as being childish, self-indulgent and weak; moreover, individuals in pain should “suffer with dignity,” where their pain behavior does not elicit negative aesthetic evaluation or seem to be exaggeratory by onlookers (p. 342).

### **A. Scandinavian Influences on Pain**

Scandinavian Americans consist of individuals with Danish, Faroese, Finnish, Greenlandic, Icelandic, Norwegian and Swedish ancestry. The highest per capita of Scandinavian Americans is in the Midwest (31%) (US Census Bureau, 2012). In particular, North Dakota and Minnesota have the largest Scandinavian presence, (30% and 25% respectively) and these are the states within my sampling area (Genetic Census of America, 2014).

Pain, for Scandinavians, is a taboo subject to talk about, as it places attention on self. The code of behavior known as Janteloven, coined by Askel Sandemose (1936), in Scandinavian

culture emphasizes adherence to the group and a spirit of modesty. The concept of Janteloven is an underlying current in Scandinavian social protocol which ranks selflessness and priority of the community above the needs of the individual (Sandemose, 1936). Janteloven's influence is strongest when individuals stand out, even trivially, and the community has a responsibility to reprimand them (Sandemose, 1936). Trying to express pain can be confused for calling attention to suffering. Therefore, individuals of Scandinavian descent with chronic pain who choose to express its impacts are at the risk of being bullied by the group in the name of uniformity. This cultural finding has direct application to my study as participants will be recruited from North Dakota and Minnesota and both states have a large Scandinavian heritage.

### **B. Latino Influences on Pain**

Latino culture includes persons who trace their roots to Spain, Mexico and the Spanish-speaking nations of Central America, South America and the Caribbean (US Census Bureau, 2012). Hispanics represent the nation's largest ethnic or race minority, with 52 million people constituting 16.7% of the United States' total population (US Census Bureau, 2012). Within this Hispanic population, nearly two-thirds (65%) self-identify as being of Mexican origin; the vast majority of Hispanics live in California and Florida (Pew Research Center, 2012).

Talking about pain with Latinos is a very different conversation. With the vast majority (55%) of the nation's estimated 34.5 million Latino adults ascribing to the Roman Catholic faith, ideations of health and illness are based on the beliefs that everything comes from God (Pew Research Center, 2014). Giger & Davidhizar (2004) explain that for Latinos, health may be a sign of having good luck or being rewarded from God for good behavior and illness may be seen as punishment. While the experience and expression of pain vary from person to person in the Hispanic culture Geissler (1998) notes, that "emotional self-restraint and stoic inhibition of

strong feelings and emotional expression are seen” (p. 184). Being tough about pain is a characteristic of *machismo* and has predominately shaped Hispanic society’s idea of what one considers to be a man (Marin & Marin, 1991).

Im, Guevara and Chee (2007) found four conclusions when it comes to the pain experience of Hispanic patients with cancer in the U.S. including machismo as well as lack of communication about under-medication, family having more importance than cancer pain, and feeling like a prisoner, meaning patients did not feel they had a voice for advocating for treatment to reduce cancer pain. The overarching theme for Hispanics experiencing pain is marginalization as they may have immigrant status, financial difficulties, language barriers, and cultural factors which situate family as the highest priority (Im, Guevara & Chee, 2007).

### **C. African American Influences on Pain**

The population of African Americans, including those who identify as having more than one race living in the U.S., is estimated at 45 million, representing 15.2% of the total nation’s population (CDC, 2013). The largest percentage of Black residents live in the District of Columbia (51%), and the state of Mississippi (38%) (CDC, 2013).

In terms of health and illness beliefs, African-Americans hold similar beliefs as Latinos where health is deemed to be in place when one is in harmony with nature and having good health may be seen as a gift from God (Lispon & Dibble, 2005). The tightly-knit, matriarchal family structure for African Americans is of high value, where family members are expected to find a way to care for loved ones in their own homes (African American Outreach Guide, 2008). Unlike with other cultures where illness is seen as a personal burden, a personal illness may be viewed as a family illness (Leininger & McFarland, 2002). Although a sense of stoicism and a value of being strong is seen in African American culture, Lipson & Dibble (2005) report that

pain expressions may be open and publically voiced by the African-American culture and medication is accepted.

#### **D. Asian Americans Influences on Pain**

The population of Asians, including those who identify as having more than one race living in the U.S., is estimated at 18.2 million (CDC, 2011). Within the Asian population, the three largest ethnic groups are Chinese (4 million), Filipinos (3.4 million), and Asian Indians (3.2 million) (CDC, 2011). The majority of the Asian population lives in California and New York, with Hawaii having the largest concentration of Asians (CDC, 2011).

For Asian Americans, showing emotions such as pain and anger are seen as signs of weakness in one's character (Leininger & McFarland, 2002). Health and illness in the Chinese culture are seen as a part of a continuum that is a part of life where the goal of the healthcare provider is to move the person closer to health (Geissler, 1998). Illness is seen as a personal burden when a member of the family becomes ill (Giger & Davidhizar, 2004). Chen (2002) acknowledges the cultural belief which says it is inappropriate to challenge those in authoritative positions and deters patients from challenging those in respected power positions such as doctors or nurses, even if the patient does not agree with the prescribed medical regimen. Sham (2003) recognizes the common belief that pain is inevitable and the medication will not provide adequate relief.

Despite cultural variations Hilbert (1984) points out that a consistent message is found throughout folklore that emphasizes the belief that pain will eventually go away or can be treated. Hilbert (1984) discusses the problem inherent with chronic pain in that it is not eradicated despite treatment: "The chronicity fundamentally alters the entire experience, especially the sufferer's conception of the affliction" (367). Kortoba (1983) states sufferers must



rely on other sources, outside of cultural folklore, to understand their pain experiences and construct their own supplemental realities to explain their persistent pain. Hilbert (1984) claims that social interaction helps sufferers to construct an alternate reality; what emerges is a chronic pain subculture where individuals with similar chronic pain experiences create new meanings and understandings mutually and normalize the experience of chronic pain, making it seem typical and understandable. This reciprocity highlights the way meaning is arrived at with others and finds its home in culture.

### **Repercussions of Pinpointing Cultural Influences**

While patterns for the meaning of pain, thresholds of pain, and coping styles differ across cultures, the complexity of culture and the variances of individual preferences and beliefs prevent the ability to create a definitive account of pain behavior for any cultural group. While the previous sections are broadly painted characteristics of cultural conceptions of pain their sweeping strokes present problematic generalities. In their attempt to classify cultural tendencies, they may oversimplify the complexity of culture and its myriad influences and instead treat it as a single, knowable object. Although they may convey overarching tendencies, they do not attend to personal preferences and beliefs which may deviate from the dominant cultural norms. The problem with these generalities is that they can perpetuate stereotypes which can lead to health disparities among different segments of the population.

Some trends regarding diagnoses and treatment are culturally specific and implicate the need for more culturally competent delivery of care (Callister, 2003). For example, fibromyalgia is likely misdiagnosed or undiagnosed among Hispanics and African Americans in primary care clinics (Caldwell, 2001). Research has documented that African American chronic pain patients report higher levels of pain and experience greater impairments in physical and emotional

function compared with Caucasian patients (Hooten et al., 2012, Edwards et al., 2001). Due to cultural particularities in pain expression, African American's chronic pain symptoms have been attributed to major depression (Alberque & Eytan, 2001). These kinds of race/ethnic differences may be reflective of disparity-related factors such as discriminatory treatment practices, access to medical care, and poor responses to treatment. Rather than focus on cultural factors influencing pain, I agree with Riley et al. (2002) who attest to the need for more attention on factors that mediate these influences. As Callister (2003) states, in the provision of health it is important that health care providers are sensitive to cultural influences on perceptions and expressions of pain. Since there is not a single, fixed definition of culture, and given the expanding culturally diverse population in the United States, there is an increased need for delivering culturally competent care.

## **V. Gaps in the Existing Literature and Strategies to Overcome the Gaps**

With this overview of issues and concepts surrounding provider-patient communication exchanges discussed in this literature review, many limitations are noted within the scholarship pertaining to the research methods and settings, research focus and research perspective. This section details these gaps found in the research studies consulted and then offers strategies to overcome them.

### **A. Bias in Research Methods & Setting**

A limitation pertaining to the methods used to explore patient-provider communication is that most of the studies employed interactional analysis of provider-patient dialogues which according to Carter et al., (1982) can best be characterized as hypothesis-generating. In regards to studies exploring disclosure practices methods are uniform in nature, with recruitment

procedures targeting patients with a given pain disorder rather than appropriateness for the study (Lumley, Sklar, & Carty, 2012).

In regards to the environment in which the aforementioned research was conducted most studies were conducted during the confines of an office visit using empirical means to analyze verbal and nonverbal communication behavior, whether it be by videotaping, audiotaping and/or observation (Beck, Daughtridge, Sloane, 2002; Stewart et al., 2000; Ha & Longnecker, 2010). In addition to the limitations already acknowledged in their studies, including a lack of consensus of what to measure, conflicting findings and lack of empirical studies pertaining to nonverbal behavior, the studies are constrained by their clinical setting in which they occurred (Beck, Daughtridge, Sloane, 2002).

Research suggests these formal settings prioritize patriarchal hierarchy and favor the privileged and expert position of the provider (Ong et al., 1995). Van Hooft (2003) claims provider-patient relationships are mediated by the forms of the professional setting and there are risks of objectification and routinization. When patients walk into examination room they are reminded of their unequal power relations by their physical vulnerability, wearing sheer gowns that expose their body; their passivity by being told where to sit, what to do, and are subjected to numerous tests where results are not always communicated, and their lack of control by being made to wait for unknown periods of time for the provider (Lorber, 1997; Grosz, 2003). All of these material constraints contribute to a deteriorating sense of patient dignity and serve as physical reminders of the symbolic distance between patients and providers (Baillie, 2009; Walsh & Kowanko, 2002).

## **Strategy to Offset Bias in Research Methods & Setting**

To appreciate the limitation of the clinical environment on provider-patient interactions, a discussion of symbolic interactionism will attempt to illuminate the prominence environment has on behavior and identity. Mead (1934) proposes an individual's identity is a social self. Through social interactions and by interacting with their environment individuals co-constitute their identity by taking in language, forming associations and getting embedded in cultural meanings (Mead, 1934). Blumer (2004) explains that individuals seek to have their identities verified by others by assessing others' reactions to their behavioral outputs to see if these outputs are consistent with an identity and are acceptable to others.

Taking into account the environmental influences which have sway on identity development sheds light on the way individuals with chronic pain negotiate their identity in a clinical setting and the extent to which they have to check, abandon, reorient or construct their language and identity (Mead, 1934). The formal settings which favor provider knowledge and expertise (DiMatteo, 1998), asymmetrical power relations inherent in a clinical setting (Ong et al., 1995) and the extent of credibility work women have to perform to gain validity from providers (Werner and Malterud, 2003; Birk, 2013; Johansson et al., 1996) indicate a need for future research on communication practices to exist outside of clinical settings.

### **B. Bias in Research Focus: Provider Centric**

Research examining patient-provider communication could benefit from more studies that detail accounts from the patient's perspective. While the health consumer movement that was initiated in the 1970s helped to depart from the patriarchal model of health care and toward an individualistic, patient-centered model has been a step in the right direction to understanding patients; concerns and involving them in decision making (Herndon & Pollick, 2002; Teutsch,

2003; DiMatteo, 1998), I suggest that patients' voices, views and desires in terms of communication preferences would be welcome contributions.

Western medicine relies heavily on evidence-based medicine (EBM) to improve medical practices which places value on clinical testing, quantitative evidence and large-scale control trials (Thorgaard, 2010). However, Thorgaard (2010) makes the argument that such reliance on EBM strategies threatens concrete, situated patient perspectives. Schwandt (2005) forewarns that we are at risk for believing in a false dichotomy where scientific rationality is gaining authority and counts as the only legitimate form of knowledge. Research has suggested that the biomedical model positions patients with chronic pain in a demoted status, one where they are viewed as helpless and unreliable sources of knowledge about their body (Jackson, 2005; Vanderford, Jenks & Sharf, 1997). Providers may question the veracity of patients' account given their high emotions and potential for distortion due to pain (Thorgaard, 2010). In jeopardy is the respect for the patient's perspective, standpoint and contribution (Juul Jensen, 2007). According to Richard Horton (2003), this lack of respect for patients' perspectives is one of the most important problems in modern medicine.

I agree with Thorgaard (2010) when he states an epistemological shift is needed so that first person perspectives and experiences are regarded not as private, unreliable events, but as important contributions to inform health care decisions. In *Women's Ways of Knowing*, Belenky et al. (1986) argue for the validation of subjective and constructed knowledge. Furthermore, they point out knowledge gained through life experiences and first-hand observations are important, real and valuable (Belenky et al., 1986). Kline (2010) reminds that using bodies and experiential knowledge as a means for understanding and as a tool for disseminating information has helped reshape the medical field. As Thorgaard (2010) asserts, a clear break from positivism and

empiricism in their tendency to dismiss patient perspectives in favor of providers' expertise and judgment is needed.

To counter the authoritative status physicians have and the elevated role scientific knowledge has in American society (Teutsch, 2003; DiMatteo, 1998), a new patient-centered approach is needed that doesn't eclipse the patient, but places value on first person perspectives (Thorgaard, 2010). Thorgaard (2010) defends the need for first person accounts when he says, "discourses for handling pain as a phenomenon in a person's life exist, and it is an epistemological as well as a normative problem if such perspectives are not recognized" (p. 109). This shift in epistemic position has profound potential for better understanding first person experiences and heeding Belenky et al.'s (1986) recommendation when they suggest we need to validate patients' identity as knowers (Belenky et al., 1986).

### **Strategy to Offset Provider-Centric Focus: Creative Expression**

One way to invite patient-centered perspectives into the conversation on chronic pain which caters to first person narratives is through using creative communication techniques such as metaphor and creative writing prompts. Heshusius (2009) observed that chronic pain sufferers lack the words to convincingly describe pain and begin to feel that nothing outside the self can be grasped. I propose that creative writing techniques can serve as the communicative bridge to a build a pain vocabulary.

The practices of creative writing and journaling have demonstrated therapeutic value for individuals grappling with chronic pain and illness (Baker & Mazza, 2007; Tyler, 2000) with specific benefits including increased awareness, providing skills for adaptation, and facilitating cognitive restructuring processes (Furnes & Dysvik, 2012). Pennebaker's (1988) study on the benefits of writing about traumatic experiences showed quantitative results; subjects who wrote

about trauma showed significantly improved immune responses, fewer visits to the health center, and reported feeling happier than the subjects who had written about trivial topics in the six-weeks following the study.

The use of metaphor to get at abstract concepts like pain is gaining traction in the biomedical model of treating pain (Biro, 2010; Heshusius, 2009; Soderberg, Lundman, & Norberg, 1999; Kabat-Zinn, Lipworth and Burney, 1988). The use of metaphor was encouraged in a study of women with fibromyalgia and was seen as a means to disclose of tacit knowledge (Soderberg, Lundman, & Norberg, 1999). As one chronic pain sufferer states in David Biro's book, *The Language of Pain*, metaphors can "help change the mindset of sufferers so that they... no longer resign themselves to dwell in pain alone" (Biro, 2010, p. 48).

Berger and Luckman's (1966) notion of language as a repository of transmittable meanings and experiences helps to show how language influences pain communication. Lakoff and Johnson (1980) have pointed out the power language has to shape the ways we see and think of things in their book *Metaphors We Live By*. Susan Sontag (1986) demonstrates this power of language when she examines how metaphors used to describe illness have influenced the way we think and talk about illness and have impacted patients' perception. Given the power of association I argue that encouraging individuals with chronic pain to communicate using creative expression, in community with others, may generate new metaphors and understanding of the chronic pain experience. As David Morris (1998) argues in *Illness and Culture*, we do not need to abandon the biomedical model but we need to absorb it into a new bio-cultural model that acknowledges the historical, cultural, psychological and social forces at play in an individual's experience. Similarly, I propose a bio-cultural metaphoric relationship of pain is needed.

### **C. Bias in Research Perspective: Positivistic Bias**

A final gap I would like to point out is that a majority of the studies consulted in this literature review have originated from positivist journals steeped in the biomedical model (DiMatteo, 1998; Maguire & Pitceathly, 2002; Lee et al., 2002; Kaplan, Greenfield & Ware, 1989; Herndon & Pollick, 2002; Ford, 1995; Duffy et al., 2004). The body, as conceived of in a scientific positivism perspective, is a universal, bounded and autonomous entity (Cohen & Weiss, 2003). An underlying belief is that the biological body is fixed, made up of systems (nervous, endocrine, immune) which function in prescribed and predictable ways; this idea serves as the grand narrative in scientific literature (Morris, 1998). Descartes (1637) offers one of the earliest and best known expressions of the idea that bodies have historically been distinct from minds. The rational mind is privileged whereas bodies of emotions are irrational, variable and fickle (Price & Shildrick, 1999). Stemming out of the Enlightenment era which declared all men are by nature equal, Schiebinger (1993) explains that scientific communities responded to this challenge by scrutinizing human bodies and found women and non-European men to possess deviations from the European male, which served as the specimen to which to compare other dysfunctional bodies. While these practices generated numerous racial mis-readings of the human body and have created scientific racism and scientific sexism, Schiebinger (1993) claims these theories highlight the need to incorporate gender as a variable when looking at research methods and data gathering.

### **Strategy to Offset Positivism: Feminism**

To be cognizant of how other researchers and paradigms approach the body and because of the high prevalence rate of chronic pain affecting women (Hardt et al., 2008; Darnall, 2011) I recommend examining the body from a feminist perspective. Donna Haraway (1991) claims the



scientific focus on defining and diagnosing pain is ill-directed because it overlooks the social location and identity of the researcher. Critics of positivists contend that their belief in a universal and external knowledge and focus on observable facts limits their view; instead researchers should reach behind the observed reality and reveal more fundamental layers (Alvesson & Skoldberg, 2010).

Feminists like Audre Lorde (1984) reject positivism and its methodologies explaining the whole process of defining privileges those with power and resources and excludes the knowledge and experience of women and other marginalized groups. Lorde (1984) further advocates that the language women use to express their pain needs to be given special consideration as the words they use are not of their own definitions, but predetermined by patriarchal conventions. Additionally, women's sense of knowledge construction needs to be examined as Belenky et al., (1986) point out women have adopted a received knowledge position and have regarded physicians as ultimate authorities. Belenky et al. (1986) continue to claim that women have looked to science for answers and alienated their own subjective knowledge as well as knowledge constructed in relation with others.

Mary Douglas (1991) claims that stemming from their reproductive capacities, female bodies have been regarded suspiciously as the site of unruly passions and the storehouse of parts that are mysterious and may be faulty. The unpredictability of the female body, the way that it changes over time with menstruation, lactation, child birth and menopause, goes against positivists' intent on prediction and control (Nastasia & Rakow, 2010; Lorber, 1997). Shildrick and Price (1999) argue these hidden functions of the female body have created a covert distrust among men who are accustomed to a more self-contained and orderly body; female bodies have

been marked as unreliable, lacking the ability to exercise rationality and grounded in their own biological functions.

From a feminist perspective, the biological body must be seen as transitioning, fluctuating and renewing (Birke, 1998; Fausto-Sterling, 1992; Hubbard, 1990). Rather than a specimen to be examined, feminists point out the body is a starting point to try to understand the ways in which a body is lived through (Shildrick & Price, 1999). Similarly, I agree with feminist Jean Jackson (2005) who argues that just as the body shifts and changes, the concept of pain must transform from a fixed definition to one that views pain as a subjective experience that incorporates mind-body connections.

## **VI. Rationale for Further Research**

As successful, humanistic medical encounter with positive health outcomes are contingent on quality communication (Teutsch, 2003) I maintain further research is needed to better understand the communication practices and preferences of individuals with chronic pain. Since research indicates chronic pain predominantly affects women (Edwards, 2013) and women predominantly seek medical care for their pain from male physicians (Kaiser Family Foundation, 2014), understanding how women's sense of identity is shaped by the belief that their source of bodily knowledge is unreliable and inaccurate can help me better attune my analysis on discourse as a means of identity formation. Moreover, the positioning of women as listeners, more than talkers (Belenky et al., 1986) provides impetus to create a framework that invites women to not only listen to, but talk with others. With the tendency to dismiss women's pain (Johansson, Hamberg, Lindgren & Westman, 1996; Werner & Malterud, 2003) I call for a new model to examine communication practices which prioritize patients' perspectives and lived experiences.

Lee et al., (2002) indicated that providers must gain an understanding of the patients' perspective on their pain in order to be effective communicators but so far, most of that information has been collected in clinical settings where medical discourse frames the interaction (Ong et al., 1995). Moreover, as Ruesch (1963) acknowledges, communication is the pipeline to human relationships and the means by which individuals influence and understand one another. Therefore, there is need to extend the review of communication practices outside the medical environment and understand patient communication preferences with family and friends as they play a vital role in a patient-centered outcomes. To address this blind spot I propose a method which is conducted outside the formal, sterile, and clinical environment of an office setting and one which prioritizes the perspective of chronic pain sufferers and their intimate knowledge from living with chronic pain.

To facilitate this communication exchange, an informal environment that is convenient and accessible only to individuals with chronic pain is preferred. To add authenticity to the lived reality of pain, I agree with Thorgaard (2010) who suggested that in order to research chronic pain we must hear from those who have experienced chronic pain personally and intimately, using their own language. Furthermore, excluding providers from the exchange can open up the discussion and allow for candid conversation, omitting the perceived physician distrust and fear of leaving home (Teutsch, 2003). Due to the constraints of language used in the biomedical discourse as discussed by Price & Cheek (1996) which work against the variation in patients' self-reports and which work to reinforce established meanings of pain (Rice & Waugh, 1989), I hold that new meanings and metaphors may emerge which can deepen our understanding of chronic pain.

One study that does take into account discourse practices of individuals with chronic pain involves examining responses posted to an online chronic pain management workshop by using thematic discourse (Becker, 2013). Results showed that individuals sought more validation and encouragement relating to their chronic pain (Becker, 2013). While this research provides an initial glimpse of communication practices among individuals with chronic pain in an informal setting, it is limited because the workshop was sponsored by a health organization. Although it was conducted using internet technology, which gets outside of the clinical environment of an office visit, the health organization's primary purpose of goal-setting may have influenced the extent of language used and responses provided. While this study is a start to understanding patient perspectives, I argue more research like this is needed so that pain sufferers can be heard from directly regarding how pain impacts them holistically and what their communication preferences are.

By encouraging participants to ask questions, to relate to one another by sharing stories and experiences, I hope to enable participants to construct knowledge together (Berger & Luckman, 1966). By inviting individuals with pain to talk openly about their lived experience and the impacts of pain through creative writing techniques, I strive to better understand what it's like to communicate about pain in the postmodern age. As a result, societal norms about when and how we talk about pain may be redrawn.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **Mixed Methods Research Design Rationale**

A mixed methods research design is the selected approach to explore communication practices and preferences among individuals with chronic pain. This chapter offers the justification for this selected method and then details how these methods attempt to answer my research questions. Creative writing techniques and metaphoric expressions have demonstrated ability to produce language to account for abstract sensations and communication preferences (Biro, 2010; Heshusius, 2009; Baker & Mazza, 2007; Tyler, 2000; Furnes & Dysvik, 2012), yet a frequent criticism against qualitative research is that it appears hard to generalize to a larger population (Firestone, 1993). While a quantitative survey tool can describe trends and attitudes of this population which can then be generalizable (Creswell, 2003), the variations in responses are limited and respondent's voices may be constrained to scripted response options (Fowler, 2002). Trying to understand the complex experience of living with chronic pain warrants the need to complement one method with another.

As explained by Johnson and Onwuegbuzie (2004) the benefits of this tandem approach to research are that communication across disciplines is accessed, collaboration is promoted, and superior research is produced. Taken together, qualitative and quantitative approaches can yield a powerful and holistic picture of communication practices and preferences among individuals

with chronic pain. According to Creswell (2008) both methods present subjective and objective findings. I contend that a mixed methods research design is a suitable approach to answer my research questions.

A mixed methods research design allows for the collection and analysis of both qualitative and quantitative data in a single study. Fry et al., (1981) outline six purposes of mixed methods research which apply to my research including: 1) enabling testing of quantitative methods; 2) improving the discovery of more explanatory concepts; 3) assisting with the explanation of the margin of error; 4) assisting in the collection of better quality data; 5) countering anomalies found when analyzing quantitative data; and 6) contributing to the generation of new ideas, insights and understandings. Everest (2014) holds that the combination of mixed methods helps to validate research results.

Beginning with Campbell and Fiske's (1959) "multimethod matrix" to examine multiple approaches to data collection, this approach has been widely used and has encouraged others to mix methods (Creswell, 2003, p. 15). The use of mixed methods research in social sciences is increasing, especially in applied research areas (Teddlie & Johnson, 2009). According to a recent literature search conducted by Roberts and Povee (2014), "publications featuring mixed methods research in applied social science disciplines are two to three times higher than in 'pure' social sciences, with an estimated prevalence rate of 6%" (p. 1315).

Similarities among the methods include both approaches describe data, fashion claims from their data, and try to explain why the outcomes they observed occurred as they did (Sechrest & Sidani, 1995). Both sets of researchers employ precautions in their investigations to reduce confirmation bias and guard against invalidity (Sandelowski, 1986). However, some quantitative purists discount qualitative methods as they are perceived to not be carried out

objectively (Onwuegbuzie, 2002). Pope, Ziebland and Mays (2000) acknowledge a criticism lodged by positivists at qualitative researchers alleging their research is difficult to duplicate and their findings amount to no more than personal impression.

On the other hand, qualitative purists may be criticized for keeping their analysis private and not providing adequate rationale for their interpretations of findings (Constas, 1992).

Johnson and Onwuegbuzie (2004) argue against qualitative or quantitative purism and contend the goal of mixed methods research is not to replace either of the approaches, but to apply the strengths and minimize the weaknesses of both in a single research design.

Benefits of a mixed methods design include the ability to minimize partiality inherent in any single method and converge data through triangulation (Creswell, 2003). Additionally, words, pictures and narratives can add meaning to numbers and alternately, numbers can add precision to words, pictures and narratives (Johnson & Onwuegbuzie, 2004). In particular to health care research, mixed methods have been appreciated from the viewpoint of validity and reliability (Morse, 1991; Morgan, 2007). A final advantage of this approach is the manner in which qualitative findings are deemed more palatable to an audience inclined toward quantitative data (Creswell, 2003). Pertaining to my intended audience of health care providers who may be somewhat unfamiliar with naturalistic findings, this mixed methods approach can serve as a bridge to accept new methods.

Weaknesses to a mixed methods design include longer time and more resources needed to collect and analyze data (Creswell, 2003). Lack of familiarity with and expertise in conducting mixed methods can minimize the likelihood of researchers from selecting this research design (Roberts & Povee, 2014). A mixed methods design can be difficult for a single researcher to

conduct; if two or more approaches are used concurrently, a research team may be required (Johnson & Onwuegbuzie, 2004).

### **Qualitative Responses Inform Quantitative Development**

My mixed methods research approach involves first conducting a six-week creative writing workshop in which participants provide textual responses to creative writing prompts. Secondly, a quantitative survey provides numeric data on communication trends among individuals with chronic pain. This mixed methods design is sequential exploratory in nature, where one research procedure elaborates on the findings of another method (Creswell & Plano Clark, 2011). The sequential exploratory strategy is conducted in two phases; the first phase is given priority and is characterized by an initial qualitative data collection and analysis which is then followed by a quantitative data collection and analysis (Creswell, 2003).

My first phase consists of collecting textual responses participants post within the creative writing workshop and analyzing them using discourse analysis. The writing workshop curriculum delves into the experience of living with chronic pain, focusing not on the sensations of pain, but the ways in which pain impacts participants' daily living.

For example, the first writing prompt asked participants to take inventory of their pain, detailing where it starts, the direction in which it moves, and patterns in its cycle. This writing prompt is similar to a health care provider asking patients to describe their pain in terms of intensity and duration, but asks participants to attend more to patterns and triggers. Along with a description of their pain, participants provided commentary on how it impacted their functionality and how they emotionally reacted to their pain. The added content on impacts and emotions revealed a potential disconnect from a straight-forward account of pain that a health care provider may value. These responses highlighted a need for a survey question to inquire



about the difference between being heard and being understood when it comes to describing pain. While individuals with chronic pain may describe their pain to a health care provider, their description may not convey information that has clinical utility in terms of helping form a diagnosis and parts of their responses may be overlooked. To try to delineate the difference between explaining chronic pain and explaining the experience of living with chronic pain three survey questions were developed to gauge how well individuals with chronic pain feel they can adequately describe their pain (survey question 9), that their health care provider understands their pain when they describe it, (survey question 10) and their health care provider understands how pain impacts their life (survey question 11).

The second week's writing prompt asked workshop participants to chart how pain impacts their day-to-day living, noting specific behaviors which have been modified or changed because of their pain. Participants discussed how pain limits their activity level and quality of life, impacts their productivity at work and at home, disrupts their ability to commit to plans and constrains their goals and dreams. From these responses, I wanted to better understand the extent of the limitations, professionally and socially. The following two survey questions were developed that inquired as to how often individuals with chronic pain have had to miss work or cancel a social outing due to pain (survey question 5) and how frequently pain disrupts their day-to-day living (survey question 6).

The predominant focus of the workshop was to explore the impacts an invisible physical sensation has on a person in tangible ways. Participants discussed the ways their way pain impacted them on a daily basis in response to each workshop prompt, whether it be financially, spiritually, romantically, emotionally, psychologically as well as physically. Given that this was a topic receiving considerable attention in the workshop, I wanted to explore ways that would

help to facilitate the disclosure of the way pain impacts them as this disclosure may enable better understanding. Often, the focus on pain communication is on describing the physical manifestation of pain, but I wanted to place focus on how to better understand the ramifications of living with chronic pain. To get at the experience of living with a concealed disabling condition that participants were describing, the following survey question (survey question 19) was developed: to better understand my chronic pain, I wish my health care provider would ask me more about how chronic pain. The list of response options was derived from workshop posts which included daily activities, social and family relationships, work responsibilities, self-image and self-esteem, and goals and dreams. To determine the extent audience has on pain communication preferences, the same question was asked specifying an audience of family and friends (survey question 20).

The fourth writing assignment asked workshop participants to write out a specific pain which they would share with spouse, family members or caretakers that outlines their preferred ways of caring for and coping with a pain flare-up. Participant responses revealed how rarely they talk about pain or share information about their pain condition with their loved ones. These responses prompted the development of survey questions to inquire about with whom individuals with chronic pain talk about their pain outside of a medical context (survey question 7) and how often pain communication seeps into everyday discourse (survey question 8).

Moreover, the reluctance to communicate their pain with loved ones revealed by workshop participants prompted further inquiry to explore if talking about pain has any emotional or therapeutic value. Several survey questions investigated the notion of therapeutic pain communication by asking if individuals with chronic pain feel talking about pain is beneficial (survey question 13 ), and if they perceive others are interested in learning about their

chronic pain experience (survey question 14). Survey questions 15 and 16 were crafted to explore any emotional value was gained when individuals with chronic pain talked about their pain with their health care provider and family and friends.

As a data set, the qualitative workshop writing responses greatly informed the development of the quantitative survey tool which delved further into communication preferences. Triangulation from the data sets can determine whether the survey results regarding discourse practices are consistent with the writing workshop responses. As Stake (2006) asserts, triangulation ensures greater accuracy in the identification of alternative explanations and this in turn informs the bases of valid and reliable results. Morgan (1998) attests to the power of the sequential exploratory strategy to test emerging theories stemming from qualitative data and claims this design can be used to generalize qualitative findings to different sample populations. Creswell (2003) testifies to the value of this approach in its ability to explore phenomena and build a new instrument.

Both of my methods are conducted through the use of computer mediated communication. The writing workshop is created through an online weblog server and all participants sign on to the private website first before posting their responses. The quantitative survey is created through Qualtrics and disseminated through online social media outlets. Since both methods involve Internet technology the first part of this methodology chapter discusses the selection of using computer mediated communication as a mode of delivery for both the qualitative and quantitative methods.

Part two details the procedures for the first phase of the mixed methods research design, the qualitative data collection, including the writing workshop's design, recruitment strategies,

procedures, curriculum, and participant characteristics. Part three offers a rationalization for discourse analysis to serve as the analytical tool to evaluate the qualitative data.

Part four provides the procedures for the second phase, the quantitative data collection, including the rationale for a quantitative survey tool to create a more refined survey for those with chronic pain. Following the discussion on the survey rationale is a description of the survey tool, its design, and sampling procedures. Finally, part five details the use of a t-test as a means to analyze the quantitative data.

### **I. Computer Mediated Communication Rationale**

In order for both my qualitative and quantitative methods to be successful in examining communication practices and preferences of individuals with chronic pain, the context in which the inquiry takes place needs to be a convenient and safe setting where individuals feel secure in discussing their pain identities. The space needs to provide a safe haven where this marginalized population (Jackson, 2005) can feel safe to disclose of feelings and symptoms using language that is their own. As suggested by Lumley, Sklar and Carty (2012) the setting needs to be a non-clinical, non-medical environment to cater toward patient perspectives. The ideal venue to explore communication preferences needs to be a more neutral, and ideological-free setting. It needs to be accessible to a limited mobility population and it needs to be an inclusive, judgment-free setting to encourage candid disclosures.

One platform that meets these needs and facilitates this type of informal communication is computer mediated communication technology (CMC). Specifically, creating the writing workshop online is the delivery of choice to tap into experiences and impacts for those living with chronic pain and to examine the therapeutic value of talking about pain. A social constructivist perspective holds the viewpoint that people actively make meaning for the words

they use in specific contexts (Berger & Luckman, 1966). James Paul Gee (2014) refers to this concept as “situated meanings” (p. 215). People customize their language in response to certain contexts and often this process is collaborative and interactive.

The ability of Internet technology to connect disparate users into a network creates the foundation for collaboration. Online websites can host multiple participants within the confines of a private workshop so that meaning can be co-constructed. Users can create what Manuel Castells (2002) calls “cultural communes” where groups use the Internet to do identity work (cited in Bell, 2007, p. 56). An online mode of delivery combines the convenience of not having to leave home with the autonomy of using technology to reveal pain identities in confidential ways. This approach allows individuals with chronic pain to form a virtual community and holds merit in its ability to gather individuals that span geographic, cultural, socio-economic and political differences and offers them the anonymity they need to disclose of personal and intimate subject matter.

### **Benefits of Computer Mediated Communication**

Utilizing computer mediated technology in health communication has been a popular trend (Sillence, 2013; Ziebland & Wyke, 2012; Cohen, 2005). The readily available and accessible Internet technology caters to a population where anonymity, confidentiality and mobility issues abound (Guillory et al., 2015). Online support groups may have many benefits, such as breaking the geographical distance between persons who share the same disease, and allowing discussions over various taboo topics in an easier way, with synchronous communication (Finn, 1995; Finn, 1999; Im et al., 2007; Klemm et al., 1999). By overcoming space and distance, the online workshop creates a community which disregards physical

boundaries and immobility and “liberates individuals from social, geographical and biological constraints of place and proximity (Miller, 2011, p. 191).

When using CMC it is important to be cognizant of cyberspace, cyberculture, and the way technology has altered communication practices. CMC taps into Manuel Castells' (2002) concept of the space of flows, which counters the space of places since geography is no longer the dominant component of communication exchanges. Cyberspace is conceptualized as a networked society in which different things move around the world, emanating from and landing in places, simultaneously (Castells, 2002).

In traditional communication exchanges and as outlined in the communication model put forth by Shannon and Weaver (1948), importance is placed on the speaker sending a message and on the response to that message. In cyberspace, more emphasis may be placed on the ideas and communication which flow through cyberspace, courtesy of the electronic circuits linking up information systems in different locations, than on the sender of the message (Castells, 2002).

Mitra (2004) contends that on the Internet, where personal voices operate within the public sphere, the emphasis shifts from being heard to being able to speak. This change emphasizes the importance of verbal expression and can help cultivate a voice, both in terms of working through the complexity of articulating phenomena that exist outside of language as well as discussing experiences that exist outside of mainstream society (Becker, 2013).

While discussing cyberculture, Pramod Nayar (2010) calls for a radical redefinition of public culture, where the “public” can be people sitting in the privacy of their homes, but engaged with a community of users from around the world (p. 44). Nayar (2010) claims this present, but separate conception of the public encourages Web users to be more interactive with their virtual audience and this concept may apply to individuals with chronic pain who are

online. In the absence of seeing physical disabilities or mal- appearances, Davison, Pennebaker, and Dickerson (2000) report participants may be more emboldened to share more. Ko and Kuo (2009) have demonstrated a positive relationship between anonymity and self-disclosure among bloggers who were embarrassed by their ailment. Their research has highlighted the benefits of websites serving as social support and promoting improvements in subjective well-being and understanding (Ko & Kuo, 2009).

Another characteristic of CMC associated with the space of flows is the concept of time, or more precisely, its timelessness. Time is morphed by the space of flows, which Castells (2002) refers to as timeless time. As a result, time is compressed. In cyberspace, time is sped up, increasing the rate of exchanges, and at the same time, time is de-sequential so at any given point, online users have access to live and archived material (Castells, 2002).

These two characteristics of cyberspace, the reduction of geographic and physical space and the fluidity of time, make the Internet an appealing platform to launch a creative writing workshop. Moreover, the continuous presence of the Internet allows users to engage with the website or the survey at their own convenience. Especially pertinent to a population with limited mobility and volatility of symptoms is the ease and convenience of accessing an online workshop or survey without leaving the comforts of their home. Its timelessness is valuable as chronic pain often interrupts sleep cycles and medication can cause sleeplessness. The ability to access current and previous posts or a survey link, at any time of the day, caters to the disrupted time flows associated with chronic pain.

### **Limitations to CMC**

It was originally thought that in cyberspace, people can escape physical disabilities and distance themselves from their physical bodies (Thacker, 1995). Cyber feminists like Donna

Haraway (1991) regarded the technologically embodied body, the cyborg, as one with enormous potential to free oneself of bodily constraints of identity, race, gender and difference. However, Lisa Nakamura (2002) has spoken against this utopic look of technical embodiment or corporeal disembodiment and argued against the supposedly neutrality of cyberspace. While the ability to escape existing biological constraints can be freeing Katherine Hayles (1999) raises opposition when she contends that bodies, whether virtual or online, are the location for subjectivity. A person's identity cannot be separated from their social and historical constructs; even when bodies go online they are still raced, gendered or disabled bodies (Nayar, 2010).

Other limitations to computer mediated communication include a user-bias towards persons who are well educated, middle-aged, female and middle class (Im et al., 2007; Kim, Lee, & Nam, 2009). Also, the African population is under-represented in online support group participation and they are more likely to turn elsewhere for psychological and social support (Kim, Lee, & Nam, 2009). Other disadvantages when using CMC for support purposes include limited access to a computer (Braithwaite, Waldron & Finn, 1999), lack of computer skills or inaccurate information due to fact that many online support groups are not supervised by physicians (Dickerson, Flaig, & Kennedy, 2000), and obtaining quality and credible information (Coulson, 2013). A further limitation is the tendency for users to post more often when experiencing a pain flare-up which results in overly negative posts (Coulson, 2013).

### **Application of Computer Mediated Communication to Qualitative Research Design**

A particular benefit of using CMC that is applicable to the online writing workshop is its ability to connect participants with unknown others who face similar conditions and use them as sounding boards. The online writing workshop functions similar to an online forum which according to health researcher Elizabeth Sillence (2013), can help users build a social and



emotional support base and lessen the effects of isolation. Online forums have been applauded for their ability to provide experiential information and advice, enable users to disclose of problems or request information, and build community with others who are “in the same boat” (Sillence, 2013, p.484).

Since the online creative writing workshop is designed for a particular intended audience, participants know they are associating with like-minded individuals who “get it.” Referred to as virtual “affinity communities,” the online communities are based on common interests, even if participants lead very different real lives outside the online workshop (Nichols et al., 2006, p.48). A sense of shared interests or experiences can help to break down barriers, promote community, and enable conversation (Sillence, 2013). Further, the anonymity of a private and secure online forum safeguards against stigma associated with chronic pain conditions (Jackson, 2005). Embarrassment and shame are common feelings when discussing the intimate nature of pain and illness (Coulson, 2013). The anonymity of an invented screen name can encourage disclosure without the risk of stigmatization.

Miller (2011) introduces the concept of “freedom of engagement” (p.191) when referring to the ability online users have when they choose when and how to engage with others. Online, chronic pain sufferers can choose to present themselves as sufferers without the threat of being viewed as complainers (Werner, Isaksen & Malterud, 2004). Anonymity is an essential component to discursive practices as there is a strong history of bias when it comes to gender and pain (Price & Shildrick, 1999; Birk, 2013; Maines, 1988). Workshop participants exercise freedom as they can control the frequency of their posts and the depth of their content. If participants are infrequent contributors, archived posts enable them to follow the thread of the conversation.

Stemming from the independent decisions users make surrounding engagement practices, Mitra (2004) argues that online interaction could be considered more meaningful, relevant or authentic. In digital environments, the concept of authenticity holds more solvency than that of credibility (Nayar, 2010). While Mitra (2004) acknowledges the multitude of voices that can be heard in cyberspace, she contends that “some can claim to have a greater legitimacy to speak about something because of their unique history and background” (p. 495). Since a qualifying chronic pain condition is a prerequisite for the online workshop, authenticity is granted to participants. As their contributions derive from their own personal experiences with chronic pain, participants’ posts may be deemed more authentic, as opposed to credible, than advice received from healthcare professionals.

Further, researchers using a qualitative research design very similar to that of mine own, targeting individuals with chronic pain through a series of five lessons and homework assignments over an eight week period, concur that Internet-delivered pain treatments are beneficial and recommend online delivery to overcome the barriers of mobility limitations, costs, long waiting lists and insufficient numbers of appropriately trained health professionals (Dear et al., 2013).

Ziebland and Wyke (2012) proposed seven domains that relate to how consumers’ online experiences have either positive or negative effects on health: (1) finding information, (2) feeling supported, (3) maintaining relationships, (4) changing behavior, (5) navigating health services, (6) learning how to relate/interpret stories, and (7) visualizing disease through still images/videos. The online chronic pain workshop attends to Ziebland and Wyke’s (2012) sixth domain of learning how to relate/interpret stories. While the objective of the online workshop is to have chronic pain sufferers develop a pain vocabulary, the use of creating writing prompts will help

participants relate their own pain story and interpret others' stories. A secondary objective is to have participants build a community of support by practicing self-disclosure within a safe and anonymous environment, thus attending to Ziebland and Wyke's (2012) the second domain of feeling supported.

## **II. Phase One: Qualitative Data Collection**

Now that the rationale for computer mediated technology as the mode of delivery for both methods has been presented I will describe in detail how the first method, the creative writing workshop, was conducted including website design, workshop curriculum, recruitment, workshop procedures, and participant characteristics.

### **Website Design**

The chronic pain writing workshop was created through a free blog offered by WordPress.com ([chronicpainvocab.wordpress.com](http://chronicpainvocab.wordpress.com)). As Michael Benedikt (1991) advises, architectural principles are needed when designing cyberspace. It is crucial to build a website that is user friendly, which works for, rather than against users (Benedikt, 1991). To this end, the Word Press blog was kept deliberately simple. All statistical data and sidebars were removed from the selected Twenty Eleven template. The stripped down website placed heightened attention on the writing prompt and most importantly, the responses.

The website was private, meaning it required a login and password to enter the site. The workshop consisted of a pre-test survey which included an IRB consent form, six weeks of curriculum with a new writing prompt posted each week, and a post-test survey to evaluate the intervention. Expectations for participant involvement included the commitment to spend two to three hours a week to post a writing response and in order to build a collaborative community, to comment on at least two other participants' posts.

## **Recruitment Strategies**

Two online writing workshops were offered. The first workshop served as a Pilot (referred to as Pilot here after) to test the curriculum, the technology interface of the workshop and generate interest in the writing workshop. The Pilot workshop was held May 19- June 30, 2014 and had 10 participants. The second workshop was held August 4- September 14, 2014 and had 9 participants. The workshop curriculum, online portal, and delivery stayed consistent for both occurrences.

## **Pilot Recruitment Methods**

To tap into an established client base of individuals currently being treated for chronic pain, the recruitment process started with a referral from health care providers at Altru's Family Medicine Residency Center, located on the University of North Dakota campus. The rationale for this recruitment process was twofold: to recruit from existing clients that already self-identified as having chronic pain and who were seeking medical care for their chronic pain conditions; and to bolster the workshop's credibility by having the provider make the referral and endorse the workshop.

To begin forging this partnership and to gain support from the medical community I presented a research proposal to Dr. Gregory Greek, head of Altru's Family Medicine, on June 10, 2013. After reviewing my research aims, Dr. Greek responded favorably to the idea of an online writing workshop targeting chronic pain patients to better understand this potential therapeutic outlet. Dr. Greek agreed to inform his staff of my research and to make appropriate referrals. I submitted IRB applications to both research entities including the University of North Dakota and Altru Health System and gained approval on December 30, 2013 and February 17, 2014 respectively. (See appendix A and B).

While I continued to make progress in my graduate program over the following months, Dr. Greek's tenure as head of family medicine expired. Therefore, I had to make a new pitch to the Altru staff. To gain buy-in from all physicians at Altru's Family Medicine, I was invited to present my research agenda at a staff meeting on February 11, 2014. I presented my proposal along with the IRB approval forms and curriculum overview. After a two week review period Dr. Greek informed me that they supported the proposal and would make appropriate referrals.

Having the physician make the referral prevented the problem of me, a non-medically trained person, having to diagnose or decide what constitutes a chronic pain condition. Selection criteria that physicians used to determine potential participants included having a diagnosed chronic pain condition such as multiple sclerosis, fibromyalgia, chronic fatigue syndrome, Temporomandibular Joint Disorders (TMJ), migraines, epilepsy, and others that had lasted for at least three months. HIPPA constraints prevented me from contacting patients directly; rather the referral process entailed Altru physicians telling a qualified patient about my writing workshop and providing them with advertisements I had given to Dr. Greek (See Appendix C). The advertisement was a one-page flyer targeting those with chronic pain. It explained participants are wanted for an online creative writing workshop and detailed the aims of the workshop. It also listed my UND email address as well as cell phone number. Interested candidates could email, call or text me with any questions or to express interest.

A small number of referrals warranted additional recruitment methods. I expanded my recruitment method to word-of-mouth which led to snowball sampling where individuals spread the word to peers who they thought would be qualifying candidates and interested in the class. This referral sampling technique is often used in concealed populations which are difficult for researchers to access (Faugier & Sargeant, 1997). Although snowball sampling is a non-

probability sample and may be subject to numerous biases, specifically creating a more homogenous sample where friends recruit friends, it is a sound choice for hidden and marginalized population such as chronic pain sufferers (Faugier & Sargeant, 1997).

### **Second Writing Workshop Recruitment Methods**

For the second workshop I endeavored to enlarge the geographic scope of participants and increase cultural diversity by employing digital recruitment methods. To tap into the informal network of mass audiences, social media was used. Timing was also a consideration; I didn't want to compete with summer travel plans so I waited to offer the second workshop until the beginning of August when school was close to starting and family schedules were falling into a routine.

Two specific online venues were selected: a chronic pain support webpage hosted through Facebook and a chronic pain management support group hosted through Daily Strength website. The rationale for selecting Facebooks is that it is the world's largest social network, boasting 1.15 billion monthly active users (Ballve, 2013). As the most popular social media site across the globe, I wanted to be able to recruit from a diverse demographic pool. The chronic pain Facebook group had 317 members, was created in August of 2013, and its primary aim is to help anyone dealing with any type of chronic pain. By choosing this recently created Facebook page I was hoping to connect with chronic pain sufferers who were newly identifying as a chronic pain sufferer and may be likely to be open to trying alternative approaches, such as participating in my online writing workshop.

To provide an alternate perspective I wanted to use a website that had a longer history and larger member base. I recruited from a chronic pain support group hosted through the Daily Strength website, a free and anonymous online community designed for people to talk to others

facing similar health challenges. Daily Strength serves as a clearinghouse for support groups, offering over 500 communities of support for a variety of illnesses and health conditions. The Chronic Pain Support Group was established in 2006 and has 6100 members.

Gaining buy-in from both of these online sites was a long process. Suspicions of scams and distrust can run high in virtual communities (Dasgupta, 2013) and both websites had dedicated gatekeepers. In order to enter the field, Whyte (1984) suggests that researchers need to identify those in leadership positions and align themselves with them in hopes they will provide useful contacts. Since I wanted to gain access to an informal community of individuals with chronic pain I needed to reveal my own credentials as a chronic pain sufferer. To gain an emic perspective, that is combining the view of the researcher and the participant (DeWalt & DeWalt, 2002) I needed to be perceived as an active and authentic member, not as an academic researcher.

To facilitate this insider perspective, I joined the chronic pain Facebook page on May 25, 2014 using my personal Facebook account which reveals my first and last name. The chronic pain Facebook page is a closed group, meaning members have to be invited by current members or validated by the gatekeeper. Using my personal Facebook account to join was a deliberate strategy as it promoted transparency and enabled me to align myself with my participants by conveying that I am a woman, a mother, and a chronic pain sufferer. With Facebook, other members could check out my personal Facebook page, view my family photos and circle of friends. In this way, members are responding to me and my physical presence as much as they are responding to my ideas conveyed in my posts. This positioning demonstrates the social constructivist perspective articulated by Lincoln and Guba (1985) when they discuss doing

research with, not on, participants. Two days later, the gatekeeper verified my status and then added me as a member.

According to Whyte (1984), asking questions or gathering data is not recommended in the initial stages of establishing rapport. I knew I couldn't recruit participants in my first post. To develop my online presence and build rapport, I joined both groups months in advance of offering the second workshop, posted often, responded to, and liked others' posts.

Approximately two months later, on July 18, 2014 once I was perceived as an insider, I posted the following invitation:

*Communicating about pain is hard--it's invisible, inaudible and immeasurable. Sometimes the best way to talk about abstract sensations such as pain is through abstract techniques like creative writing. I am teaching an online creative writing workshop aimed at trying to better develop a pain vocabulary. The class is free and starts August 4 and goes 6 weeks from there. No writing background is needed. There are a few slots open so message me if you are interested.*

The group's moderator blocked this post and didn't allow it to be released to the group until I presented research credentials. To satisfy the demands for legitimacy, I scanned UND's IRB approval form. The gatekeeper then kept the digital IRB copy in the chronic pain support group's files and released my post. To enroll, interested individuals sent me private messages through Facebook.

I joined the Daily Strength chronic pain support group using a pseudonym (purplepain17) for my screen name on May 28, 2014. Using a pseudonym was the norm for this group as most members created pain names or pain personas that differ from their given name. I used the default avatar which is a black and white profile picture as I wanted to remain anonymous. In



order to gain entrée into the group and be accepted as an insider I actively posted to the discussion board and responded to others' posts for nearly two months before posting my invitation. On July 20, 2014 I created in a New Topic tab within the Chronic Pain Support Group website and posted the same invitation that was on Facebook.

### **Writing Workshop Procedures**

When a message of interest was received I responded by explaining the workshop goals. If members wanted to enroll, I asked for an email address to better facilitate communication exchanges and have a secure communication channel. When potential participants emailed me they received the following message with an embedded link to a pre-test survey created in Qualtrics which included the informed consent:

*I am pleased to learn of your interest in the online chronic pain writing workshop. The class is called "Developing a Chronic Pain Vocabulary by Writing our Pain Story" and is designed to tell our story in our own words. This class is more about the experience of what it's like to live with pain, more than on any particular condition. You don't have to divulge of personal details or conditions unless you want to.*

*No writing background is needed for this class. Sometimes, because pain is so abstract and subjective, we need creative methods to tap into that sensation. There is no wrong answer and there are no grades. I'm hoping to devote some time and attention to a topic that is socially taboo and culturally discouraged from talking about. In that way, we can help each other express a private and personal phenomenon. All participants of the class have some sort of chronic pain and "get it" to the extent they we will be forming a community of support.*

*The workshop is created through Word Press and it's a private blog meaning no one else can access it. I have created a unique username and password just for you that will take you right to the webpage. Shortly, I will email you with a unique login and password that will take you directly to the site.*

*In the meantime, please complete this survey. I am a graduate student at UND in the Communication and Public Discourse program and am studying chronic pain management. This workshop is offered as part of a graduate research study and has been approved by the University of North Dakota's review board. To that end, I need everyone to complete the informed consent question on the survey.*

*You can copy and paste the survey link into your browser:*

*[https://und.qualtrics.com/SE/?SID=SV\\_cHYRLT8YH28tqU5](https://und.qualtrics.com/SE/?SID=SV_cHYRLT8YH28tqU5)*

Each participant was emailed a unique login and password which allowed them to enter the site directly. To protect participant identity, once participants gained access they could change their username and password as well as upload a photo or create their own avatar to represent their online depiction. A follow-up email was sent containing the website access information and tips to customize and navigate around the blog.

*Dear \_\_\_\_\_,*

*I have created a username and password for you to enter the website.*

*<http://chronicpainvocab.wordpress.com/>*

*login: painblackXX*

*password:*

*Once there, you can click on the username icon on the upper right hand corner and click on Settings. You can change the username if you like. You also have the option of changing your password and uploading your own image.*

*Click the back arrow (upper left corner) to get back to the page. If at any time you get lost in cyberspace and need to navigate back to the blog, here is the quick link:*

*<http://wp.me/P3VCqJ-W>*

*Please let me know if you have any problems with the website or technical issues. Please post a response to the writing prompt in week 1 and enjoy reading what others have shared--some powerful things!*

*I'm happy to have you in the class.*

*Karin*

### **Informed Consent**

The first question on the survey was the informed consent form. Consistent with IRB protocol, participants needed to be fully aware of the purpose of the survey and the nature of the researcher's intent. The exact wording of the informed consent was as follows:

*This survey seeks to collect information about your experience with pain. The information collected by this survey will provide the means to better understand pain sufferers' description of pain and preferences in talking about pain and will be used for educational research purposes.*

*The results of this survey are anonymous and will be kept confidential. The survey consists of 22 questions and should take you about 7-10 minutes to complete.*

*This survey is voluntary and you can stop at any time without any recourse.*

*If you have any questions or comments about this study, the researcher would be very interested in talking to you. Please do not hesitate to email the researcher at*

*[karin.becker@email.und.edu](mailto:karin.becker@email.und.edu)*

*By clicking on the "Yes-participate" button below, you agree that you are consenting to participate in this study. If you do not want to take part in the study, click on the "No-refuse" button below.*

*Thank you!*

*I agree to participate in this study*

- Yes-participate*
- No-refuse*

Once the participants selected the “Yes-participate” answer, they were asked to create a 7-digit PIN number. This PIN number served as a user identifier. Since the nature of the workshop dealt with a subject matter for which a stigma may be attached anonymity needed to be maintained. Therefore, the survey did not ask for any identifying information such as name or birthdate or chronic illness condition. The use of a 7-digit PIN number maintained anonymity and at the same time worked as a tracking number so the pre and post tests could be pinpointed to the same user. The participants were instructed to write down the 7-digit PIN and cautioned they would be asked for the same PIN number at the completion of the workshop.

### **Landing Page**

Once participants logged into the chronic pain writing workshop, the Welcome page loaded (See appendix D). This served as the landing page and provided the overview of the workshop as well as its aim to help individuals with chronic pain explore and express their pain. For aesthetic feel I uploaded a mountain landscape image I took featuring a stormy sky. The

brooding clouds hanging over a vibrant meadow of green grass set an emotional backdrop to the webpage.

The text on the Welcome page also conveyed the class size so participants would know the intimate nature of the workshop. As participants knew I was conducting this workshop for research purposes I was aware that they may feel restricted about their ability to discuss their participation with non-participants. I explicitly gave them permission to talk about the workshop or any posts with friends and families outside of the workshop setting.

Like a syllabus, I outlined the schedule of prompts, policies and practices. Each Monday I displayed a new tab, called Week 1, Week 2, etc., which discussed the weekly writing prompt. To remind participants of the new prompt, I sent email reminders to all participants on Monday mornings with a brief overview of the week's prompt and the shortlink to the website. Participants were encouraged to post by Thursday of the week so they could have the weekend to read recent posts and comment on them.

Anticipating that participants would likely reveal personal information, the Welcome page stressed there was no judging or grading. Participants didn't need to worry about their writing skills or grammar. To create a tone of inclusion the Welcome page reiterated no writing background was needed and there was no wrong way to answer the question. Rather, participants were encouraged to be bold in their own authority as their lived experience with chronic pain is uncontested. The Welcome page stated "We hold all of the authority to write our story. This class hopes to empower you to use your expertise, insight and ultimately, your voice to better express and advocate for your needs." Participants were free to respond in their own style using their own words.

Finally, the Welcome page outlined four goals for the workshop derived from Jones, Lookatch and Moore's (2013) theoretical model that outlines key skills chronic pain patients need to have to successfully manage their pain: understanding, accepting, expressing and learning from pain.

- ***Understanding** refers to patients having some basic knowledge about their pain condition and in particular, understanding how the mind and body interact to and respond to pain.*
- ***Accepting** refers to the patients' understanding and attitude towards the pain condition.*
- ***Expressing** refers to the ability to describe pain accurately, to convey it through language and disclose of it to others. Giving voice to our pain brings it out of the invisible, inaudible realm and may give it legitimacy and power. Disclosing of our pain to others helps us build a community of support and fosters inclusion and understanding.*
- ***Learning** from our pain allows us to be teachable, to be open to seeing pain as more than something to avoid but as a tool to better understand ourselves and our bodies.*

To begin the workshop a hyperlink to Week 1- Taking Inventory was inserted at the bottom of the Welcome page. There was also a "Like" button that participants could click on and a "Leave a Reply" box where participants could post initial comments about the workshop.

### **Writing Workshop Curriculum**

The aim of the workshop was to help individuals better observe, describe and take stock of their chronic pain so that they can better communicate it. Throughout the six weeks of the workshop, the hope is that by better observing pain, participants may better note patterns and trends and gain a deeper understanding of their pain. The goal of the workshop was not to reduce pain severity, but to increase the opportunity for pain expression. To better understand the

curriculum an overview of each week's writing prompt follows. Complete workshop curriculum can be found as Appendices E-J.

Week One asked participants to take stock of their pain, noting how pain moves across their body, its direction and patterns. This prompt is informed by Bader et al.'s (2012) mindfulness-based intervention study where patients tuned into their pain and had their attitudes about pain changed as a result from increased body awareness.

Week Two explored the impact pain had on daily living. Participants compared how they conducted day-to-day tasks when they felt pain-free compared to when they had a pain flare-up. This side-by-side comparison facilitated an awareness of the behavioral changes pain causes.

Week Three invited participants to write a pain credo where they wrote a statement of personal beliefs based on their experience of living with chronic pain. The writing prompt began: "This much I know is true from living with chronic pain..." Writing declarative statements based on their lived reality invited participants to use their own experience as knowledge and supports Thorgaard's (2010) recommendation for more first-person accounts. The ability to use personal experiences as knowledge taps into Belenky et al.'s (1986) argument for the validation of subjective and constructed knowledge. Knowledge gained through life experiences and first-hand observations are valuable, real and relevant (Belenky et al., 1986). The assignment to craft a credo based on this first-hand observation hoped to cultivate confidence and authority.

Week Four asked participants to write a pain plan with the intention of making this plan available to family members and care takers. The writing prompt asked them to list the medications they take, dosages, and pharmacies where they fill scripts as well as other accompaniments, remedies and preferences they favor when they are having a pain flare-up. This writing prompt is in response to Umberger et al.'s (2013) findings that family members are

affected by a pain sufferer's health. The strains and uncertainties of pain and illness can apply enormous pressure on family systems (Umberger et al., 2013). Parental chronic pain has been linked to emotional difficulties in children such as depression, anxiety, aggression and interpersonal difficulties (Chun, Turner & Romano, 1993). Umberger et al., (2013) have found that adolescent children of chronic pain parents who are unable to express their pain symptoms and pain impacts are more likely to endure hardships, distance themselves, lament losses and hide their authentic selves. Inconsistency or absence of caregiving by the chronic pain parent can lead to insecure attachment of the child (Umberger et al., 2013). Called the "heavily shrouded parent", this population of parents was classified as "hands off" and frequently isolated themselves (Umberger et al., 2013, p. 4). The writing prompt for Week Four aimed to unshroud the parent with chronic pain. By being explicit about their pain preferences, participants were trying to facilitate the process of receiving help from others in ways that is on their terms.

Week Five highlighted creative writing techniques by asking participants to create a metaphor or character sketch for their pain. The power of metaphoric thinking as a therapeutic tool has been demonstrated to be of value to patients in both qualitative (Biro, 2010; Heshusius, 2009; van Hooft, 2003; Soderberg, Lundman, & Norberg, 1999; Kabat-Zinn, Lipworth and Burney, 1988) and quantitative studies (Pennebaker, 1988). As Lakoff and Johnson (1980) note language has the power to shape the ways we see and think of things. Further, Sontag (1986) claims that metaphoric thinking has the power to shape cultural associations. The writing prompt sought to examine the ways participants use creative language to depict their pain.

Finally, in Week Six, participants were prompted to write a thank you letter to their pain. Specifically, there were asked to reflect on the relationships formed, events encountered or responsibilities excused from because of pain. This writing prompt took an against-the-grain



look at the experience of pain and asked participants to explore benefits as a result of living with chronic pain. Again, using Lakoff and Johnson's (1980) claim that language has the power to shape our perspective, this prompt sought to encourage new, potentially positive, associations with pain.

When workshop participants posted a response it was immediately made public to all users. Since all users were invited participants to a private blog there was no moderator filtering the responses which provided a sense of immediacy and rawness to the posts. Participants could choose to post a new reply as well as reply to another participant directly. Some participants responded back and forth to each other, creating a nice thread and inviting other participants to join that conversation. Under the provision that all participants had read the consent form and understood the workshop was conducted as part of a doctoral student's research, comments were appropriate and none were deleted.

### **Writing Workshop Validity**

The writing workshop curriculum was developed based on Jones, Lookatch and Moore's (2013) theoretical model that posits key skills chronic pain patients need to have to successfully manage their pain are understanding, accepting, expressing and learning from pain. With these tenets, I derived six prompts to delve into the experience of living with chronic pain. This curriculum has limited validity and reliability as it is original work and has never been used before. Using the same workshop design, curriculum, online server and workshop procedures strengthened instrumentation validity. Also, the six-week duration of the workshop precluded the risk of participant maturation. However, as discussed by Creswell (2009), two threats to workshop internal validity are the selection process and participant mortality. In regards to selection process, the design of the workshop emphasized writing aptitude and therefore

participants with strong writing skills may have been predisposed to enroll in the workshop. Moreover their ability to adequately express themselves through writing may have caused them to contribute more articulate responses and thus gain more feedback from others. Two strategies used to limit selection bias was employing a random selection process for participants and creating a judgment-free atmosphere in the workshop.

Secondly, there was a moderate attrition rate to the workshop participants. Although 19 participants enrolled in the workshops, only 15 completed it. One participant expressed initial interest in the workshop, but never logged on to the website. One participant dropped out due to chronic pain flare ups and subsequent treatment at the Mayo Clinic; one had a family emergency, which in turn exacerbated her physical pain to the point she was unable to participate in the workshop, and one was unable to access the website from her work computer and she didn't have time to complete it at home.

During the course of the workshop, not all participants responded to every post. Again, the nature of unpredictable chronic pain caused some participants to not respond. Some participants emailed me privately to explain their lack of participation. Mortality may lessen internal validity as the outcomes are unknown for these participants that started the workshop but were unable to finish.

In terms of external validity, Tuckman (1999) notes the interaction of participant selection and treatment can hamper findings as narrow participant characteristics may limit broader generalizability. The opposite of this may impede my research as instead of focusing on just one chronic pain condition, like fibromyalgia, and recruiting from within that condition's sample pool, participants were recruited from the larger sample of chronic pain. As a result, the variety of chronic pain conditions represented may limit the findings. The only pre-requisite was

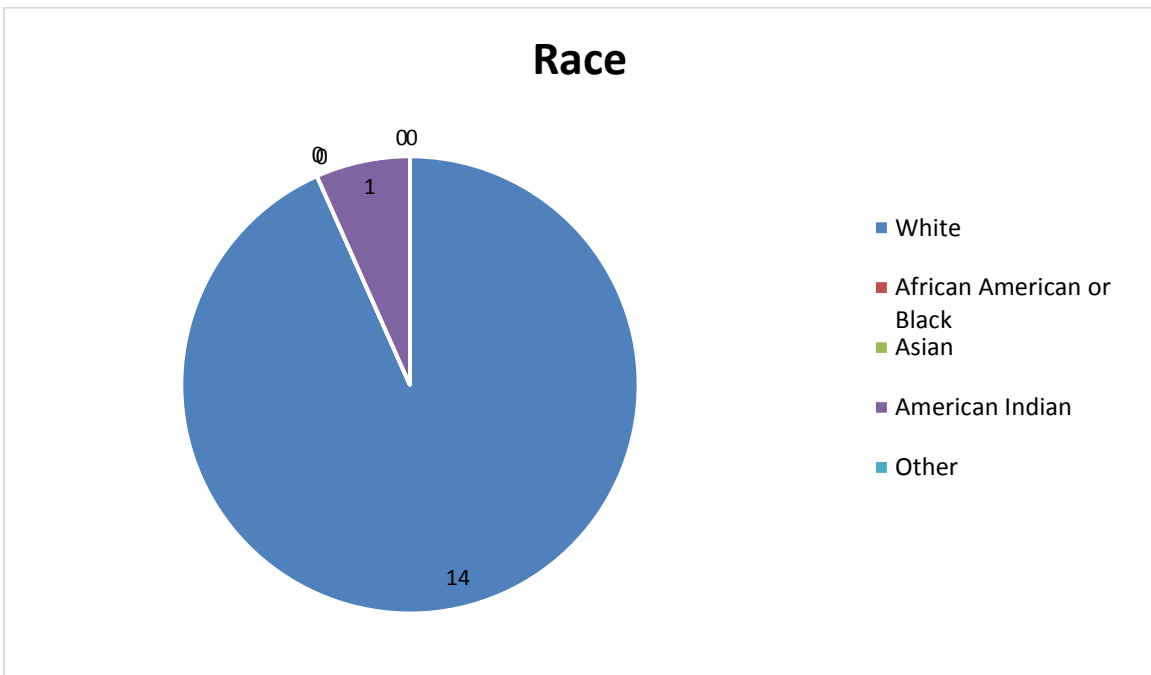
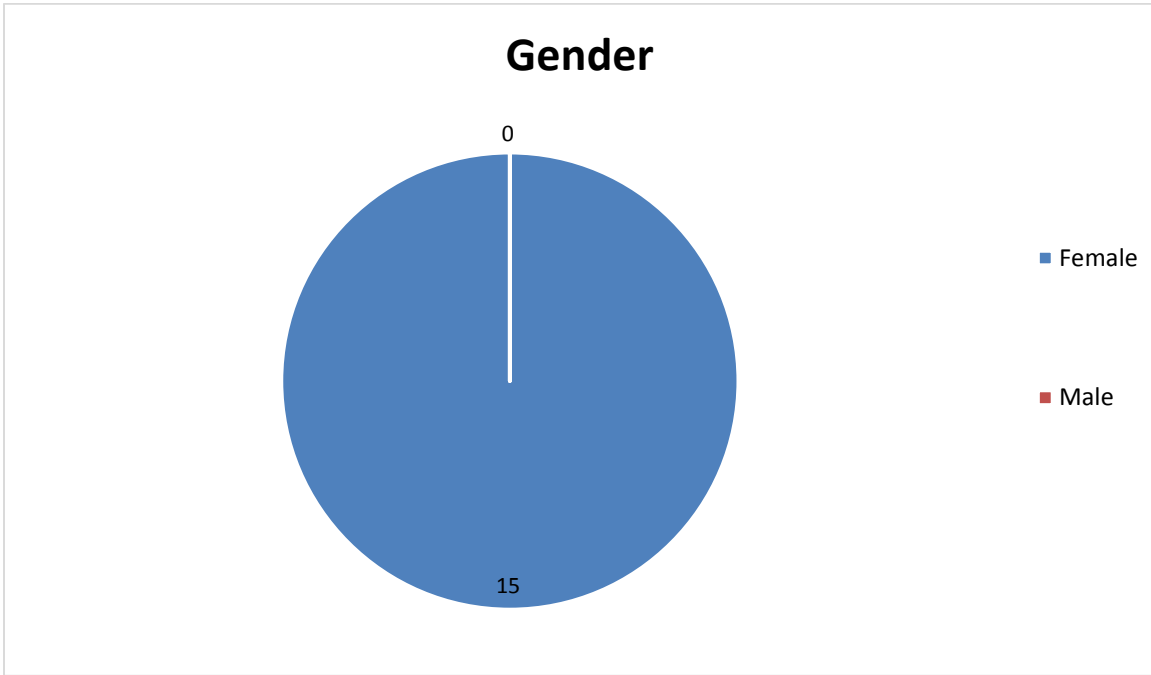
that participants had a chronic pain condition, but they did not need to disclose of it. The focus of the workshop was to explore the impacts of living with chronic pain and not on focusing on one particular condition. Therefore, because of the variation in types of chronic pain, findings may be restricted as each chronic pain condition has its own characteristics. Nonetheless, the constancy of examining the impacts of chronic pain as a whole enables me to generalize the findings to the overarching category of chronic pain.

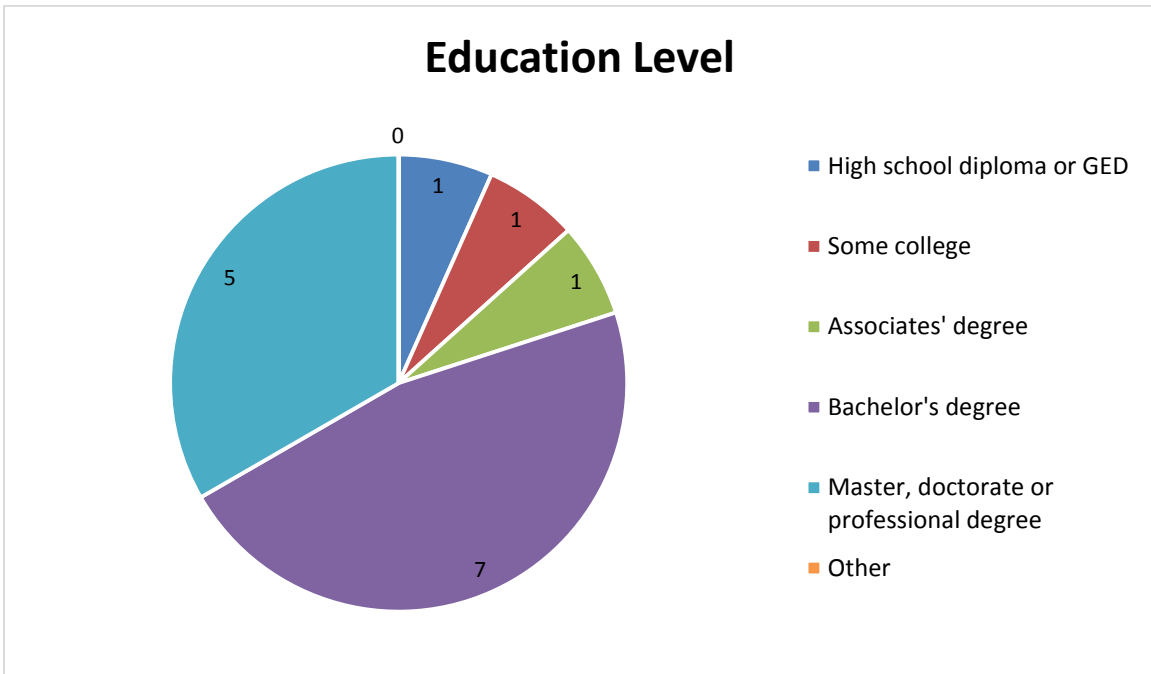
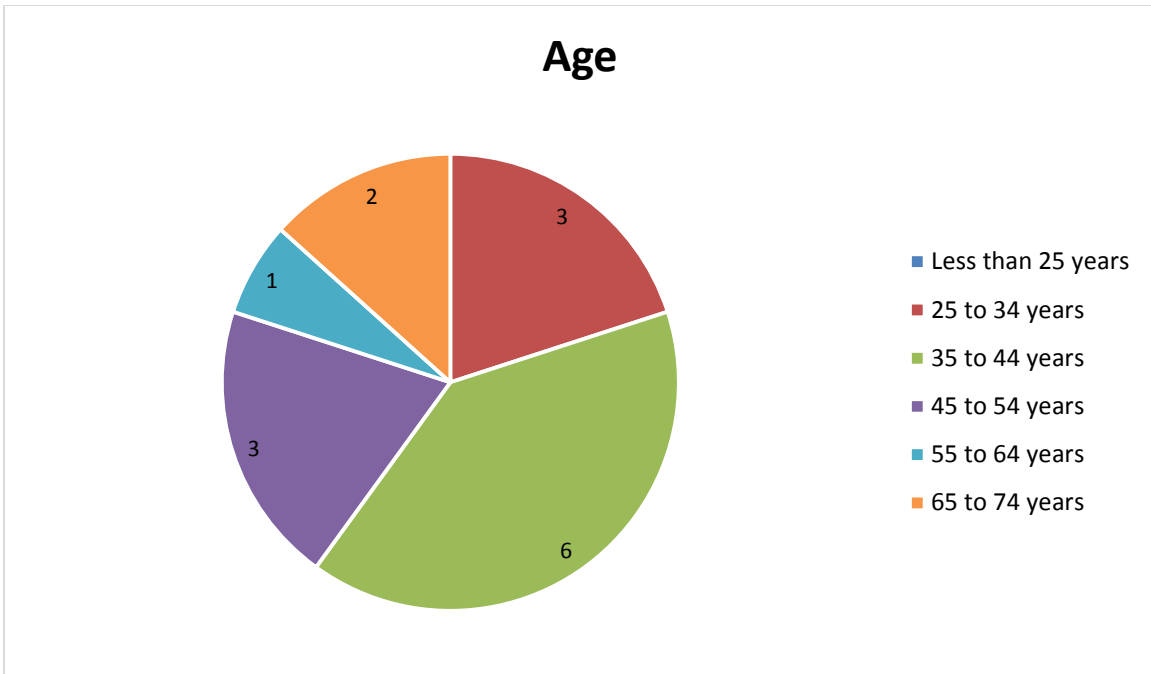
### **Writing Workshop Sample Size and Participant Characteristics**

For the Pilot, chronic pain patients living in northeastern North Dakota and northwestern Minnesota were invited to participate in a free, online chronic pain writing workshop. Ten participants who fulfilled the criteria agreed to participate. From this group of 10, nine completed the workshop. All participants were females and identified as White as the race that best described them. The age range varied with two participants aged between 25-34 years; four participants aged 35-44 years; two participants aged between 45-54 years and one participant having 65 years or more. In terms of educational levels, six participants held a bachelor's degree and three held a master's, doctorate or professional degree.

Nine participants signed up for the second workshop, with six completing the workshop. The online recruitment methods enlarged the geographic scope as urban locales were represented: Chicago, IL and Atlanta, GA. All were women, with five identifying their race as white and one identifying as American Indian. There was an even distribution of age as one participant had between 25-34 years, two participants had 35-44 years; one participant had between 45-54 years, one participant had between 55-64 years and one participant had 65 years or more. Educationally, one participant had a high school diploma, one had some college, two had a bachelor's degree and two had a master's, doctorate or professional degree.

Overall, 19 participants signed up for the online writing workshop, with 15 completing it. Combined workshop participant demographics are represented in Figure 4 below.





**Figure 4. Workshop Participant Demographics**

### **III: Phase One: Qualitative Data Analysis**

#### **Rationale for Rhetorical Discourse Analysis**

Rhetoric has been defined by Hauser (2002) as “the use of symbols to induce social action” (p. 3). To analyze the way language achieves or does not achieve its desired social action, a rhetorical technique of discourse analysis can help look at the narrative elements within the online writing workshop posts as a means to understand the participants’ motivations and identifications (Iversen, 2014). Discourse analysis is the method of inquiry to explore these narratives for insights to understand participants’ meaning and value to the experience of living with chronic pain. By applying a rhetorical discourse analysis lens to the participants’ posts they can be viewed as narratives and as such, as statements of facts and tools for representation (Iverson, 2014). Although creative writing methods were employed in the writing workshop to help participants craft their posts, the participants’ discourse is not to be viewed as invented poetry.

Based on Bitzer’s (1968) idea that rhetorical discourse is aimed at specific audiences for specific reasons in specific situations, rhetorical discourse analysis highlights the way that participants’ posts were adapted to three specific functions: contexts, audiences and purposes. First, the virtual context of the online writing workshop added a sense of distance as participants did not know with whom they were communicating, but also a sense of immediacy as posts were immediately uploaded. Both of these elements of distance and immediacy influenced the communicative framework in which participants communicated with one another. The function of context is also highlighted as the types of speech used by individuals with chronic pain in an informal, anonymous, casual setting of an online workshop with other chronic pain sufferers yielded different types of language than sufferers use in a clinical, formal setting with their

providers. The importance of the social context is critical to the analysis of what was said and how it was said. Discourse analysis acknowledges the social context of the speech act, rather than just the content or frequency of words.

Secondly, rhetorical discourse is directed at a specific audience. The focus on audience in rhetorical discourse analysis is reinforced by Scott and Lyman's (1968) concern with the feature of talk, specifically its ability to give and receive accounts. The emphasis on accounts draws specific attention to the practical function of rhetorical discourse as language is oriented to others. In my research, audience incorporates the ongoing negotiations between the participants and me as facilitator as well as communication among participants.

Thirdly, the purpose of narratives in rhetorical discourse can be as Rowland (2009) suggests, either epistemic, where the narrative functions as a tool for understanding the world, or persuasive, where the narrative "creates a sense of identification" between the subject matter and the audience and helps "break down barriers" through its ability to show different world views, emotions and images (p. 122). These narrative functions of rhetorical discourse analysis support both Bitzer's (1968) notion of rhetoric as a means to an end and Burke's (1951) notion of rhetoric as identification where identity is built on notions of agreement or disagreement with an identifying idea, world view or image. As a result, the object of rhetorical discourse analysis is to look at discourses that serve argumentative functions and the ways in which these discourses influence audiences (Iverson, 2014).

As an interdisciplinary type of content analysis, discourse analysis focuses on systems of meaning and how particular labels or concepts are developed and made powerful by the use of language (Treadwell, 2011). It is influenced by the understanding of language as a meaning constituting system, where meanings are produced by dominant discourses and are socially and

historically situated (Cheek, 2000). Two main premises of discourse analysis are that a) language can be analyzed not just on the word or the sentence, but also on the level of the context; and b) the idea that language should not be analyzed as an abstract set of rules but as a tool for social action (Bhatia, Flowerdew & Jones, 2008). First, discourse analysis proposes the language we use and the ways in which we use it are not pre-determined or anchored to some set of objective properties (Woofit, 2005). Rather, language is contingent on the social context. Instead of focusing on the form and shape of verbal utterances themselves, discourse analysis posits it is the social contexts in which words are used and the specific interactional tasks for which they are designed that become the primary subject of investigation (Woofit, 2005).

Additionally, discourse analysis enables an analysis that prioritizes words and regards them as action; as words describe, they perform a social activity (Woofit, 2005). Gilbert and Mulkay (1984) concluded language is social action after studying voluminous qualitative data stemming from scientific findings. In scrutinizing the data they realized the extent of variations in the accounts, even though the scientists were observing the same thing. The particular uses of language, terminology, style, and tone revealed the scientists' assumptions, affiliations, and memberships. By arguing that descriptions cannot be treated as neutral representations of objective social reality but rather, discursive practices can construct or undermine the factual status of a knowledge claim, Gilbert and Mulkay (1984) demonstrated that language is not a representational medium to a scientific audience.

By combining insights from both rhetoric and discourse analysis, rhetorical discourse analysis provides the ability to view the writing workshop responses as narratives which produce accounts. The accounts are descriptions or self-reports about what it is like to live with chronic pain and are shaped by the participants and in turn, shape the participants. As participants form



their responses, they use language to interact with others and construct meaning. Rhetorical discourse analysis provides the ability to propel the analysis beyond structural moves and patterns in the accounts and examine the accounting practices as arguments for identity.

Rhetorical discourse analysis as an analytical tool can assist my analysis of the qualitative writings produced in the online writing workshop as the words participants choose to describe their pain can reveal not only surface level meanings, but also indicate deeper levels of social, cultural, political and historical context (Cheek, 2000). The words participants use to describe things are what Austin (1975) refers to as being evaluatively loaded, meaning they reflect familiarity with language, metaphoric associations, distinctive vocabulary, illustrations, tropes, clichés and figures of speech. In particular rhetorical discourse analysis can examine concerns such as agency, legitimation, and controversy that are particular to the experience of living with chronic pain and which may arise in the online writing workshop.

Three concepts germane to discourse analysis that assist in identifying broad discourses which participants use to define their identities are interpretive repertoires, stake and scripts (Silverman, 2011). First, the concept of linguistic repertoires, as adopted by Gilbert and Mulkey (1984), aids in the task of summarizing global patterns in qualitative data. Repertoires are the building blocks through which people develop accounts and versions of significant events in social action and show how descriptions are constructed in contextually appropriate ways (Wetherell, 2006). They organize related sets of terms that are often used with stylistic and grammatical coherence in a systematic way. In this way, interpretive repertoires aid in the construction of a chronic pain vocabulary.

Secondly, the concept of stake helps to look at participants' interests by closely scrutinizing conversational detail (Silverman, 2011). By examining one's stake, participants'

desires, motives, and allegiances may be revealed which can help explain the significance of their action (Potter, 2004). Thirdly, the concept of script refers to the way participants construct events and helps to understand the ways in which participants attend to the normative character of their actions (Silverman, 2011). Attending to discourse patterns can reveal if the language seems scripted, as if it is the description of events is expected or anticipated and thereby normalized.

Participants are responding to me as the developer of the website and the curriculum and the one responsible for recruiting all participants personally, as well as to the writing prompts. The use of interpretive repertoires allows my positioning to be accounted for and assists in analyzing the variations in descriptions posted by participants to the same writing prompt. In particular, interpretive repertoires provide a framework in which to examine the wider nexus of desires, hopes and affiliations which characterize everyday human action, but which are exacerbated by chronic pain.

### **Discourse Analysis Coding Procedures**

The analytic scheme used in this study begins with analyzing participants' posts within the context of that week's writing prompt. These prompts invited open-ended responses of varying length and detail. Since the same curriculum was used and delivered in the same sequence on the same weblog, responses from the two workshops were aggregated to present one integrated analysis.

As Sandelowski (1995) suggests, the thematic data analysis began by reading all of the responses multiple times to gain a sense of the whole, look for patterns and comparisons, and to immerse myself in the data. To assist with data analysis all posts were uploaded into the software program NVIVO to qualitatively code the textual responses. NVIVO is a digital scholarly tool

that assists in analyzing qualitative data. The computer software is aimed at helping researchers manage, shape and make sense of unstructured information and has been used by government agencies, businesses and academics to analyze qualitative raw data including focus groups, open-ended survey responses, interviews, content analysis and ethnography (QSR, 2014). To organize the numerous emerging codes, Weiss' (1994) method of open coding, sub-coding, and local integration were implemented.

First, open coding was employed by writing general themes on a separate sheet of paper, accompanied by a tally of how many times that theme occurred. As recommended by Cheek (2000), asking questions such as “Why was this said, and not that?” “Why these words?” helped put the focus on word selection and highlighted social context. Priority was given to the themes that had the most tallies which according to Weiss (1994) “represent recurrent or underlying patterns” (p. 157). Then sub-coding was used to organize the themes and envision possible ways to categorize the data. NVIVO assisted with the sub-coding process by allowing the creation of “nodes” to represent each theme and “trees” to show the relationship between the nodes. The nodes and trees helped to conceptualize the themes into hierarchal levels and qualitatively map the data. The ability to visually organize and arrange the clusters helped to see connections among the themes.

The power of NVIVO's functionality was seen in its ability to create word clouds of specific words and their synonyms which can show both frequency of an idea, the variation in how it was expressed, and produce a visual reference for documenting and archiving. See Appendix K. For example, the theme of invisibility was frequently cited but its context was different. One participant mentioned that because her pain is invisible it is a huge hindrance and people respond to her negatively; another participant wrote that she was thankful her pain was

invisible because she can choose to keep it private and hidden. While both posts fall into the category of invisibility, they connote different meanings. Rather than just show frequency of a word, the word clouds helped to illuminate the variation with its use. The use of word clouds helped to carry out Weiss' (1994) final step of coding data, inclusive integration, which knits together isolated responses into a single, coherent story and helps to develop a substantive framework.

Once each post in response to the weekly writing prompts was coded, the thematic codes were reviewed using a constant comparative method of analysis to look at emerging patterns of all responses, regardless of which week they appeared (Strauss & Corbin, 1990). The emerging themes stemming from the writing workshop then informed the second phase of this research design, the quantitative survey. Participation by workshop members functioned as a focus group with their input informing survey design choices. The opportunity to hear from participants in their own words in a casual and anonymous setting helped me better understand how pain impacts their day-to-day living.

### **Unit of Analysis**

The unit of analysis employed in this study was the sentence. Each post provided by a participant was divided into sentences, and each sentence was categorized into themes. In the case of compound sentences, a sentence was divided into multiple sentence fragments which may represent two or three thematic categories. For example, the following post of “I just kind of give into the flare days for the most part...or take pain meds and fight them...with gusto. ..I tend to be an all or nothing person...” would be divided into three sentences---“I just kind of give into the flare days for the most part” and “take pain meds and fight them with gusto” and “I tend to be

an all or nothing person”—and coded as permission giving, self-care, and discontinuity respectively.

### **Content Validity**

As Robert Weiss (1994) contends in *Learning From Strangers*, respondents involved in a qualitative interview do not invent events. By viewing the writing workshop as an opportunity to conduct respondent interviews with individuals who have chronic pain to learn about their experience living with chronic pain this perspective suggests that participants would not falsify information. While participant response may suffer from gaps in memory and detail, their posts can be regarded as truthful (Weiss, 1994). Moreover, since workshop prompts inquired about personal experiences, tendencies for group think and group effect were low (DeWalt and DeWalt, 2002).

### **Generalizability**

Firestone (1993) outlined a case-to-case generalization as one of three types of generalization in qualitative studies that move from the particular to the general. A case-to-case generalization entails a focus on the degree of fit which the situation studied matches other situations of similar interest (Schofield, 1989). The particular findings of the thematic analysis and survey findings can apply to a larger chronic pain population because as Stake (1995) argues the concept of naturalistic generalization enhances our understanding of other situations by applying the findings from one study to other similar situations. The recruitment procedures involving recruiting participants from inside chronic pain devoted social media sites enables this application of findings as individuals are self-identifying with the targeted population. Further, Shkedi (2004) maintains case-to-case generalization holds in narrative research which produces thick descriptions. While the process of case-to-case generalizability does not engender

prediction, it can provide a realistic expectation of what may ensue in analogous situations (Geertz, 1973).

## **Phase Two: Quantitative Data Collection**

### **Survey Rationale**

To further investigate how individuals with chronic pain prefer to communicate about their pain impacts the thematic findings were used to inform a survey design and complete the mode of inquiry. In order to garner a broader representation and a larger sample of individuals with chronic pain a quantitative survey was designed to provide a numeric description of trends and attitudes pertaining to communication practices of individuals with chronic pain. The strength of survey research lies in its ability to ask people about their firsthand experiences—their feelings, perceptions and what they have done or would like to do (Fowler, 2002). Survey questions were designed to answer my research questions, with two to four survey questions grouped together to target each research question.

The purpose of the survey was to ask individuals with chronic pain direct questions regarding their personal pain communication behaviors, including with whom they talk about their pain, how frequently they do so, and how supported they feel as a result so that inferences about their communication practices could be made. Additionally, the survey inquired about what they would like to be asked from their physicians and family and friends in regards to their chronic pain so inferences could be made about their communication preferences. The ability to identify these attributes from a small sample group of individuals and generalize them to a larger population makes a survey a powerful research tool (Fowler, 2002). Alongside the qualitative data gleaned from the online workshop writing participants, the survey results present a holistic picture of communication practices and preferences.

Since the literature review highlights the importance of the communication exchange between provider and patient, the survey inquires about the extent of clarity of that communication. While survey questions inquire about clinical exchanges, they are asked outside of a clinical environment. This non-medical context is critical as it is noted that clinical communication exchanges are ranked with hierarchy that favor the physician (Ong et al., 1995).

### **Survey Design**

Given the value of anonymity, confidentiality and convenience already discussed (Guillory et al., 2015; Finn, 1995; Finn, 1999; Im et al., 2007; Klemm et al., 1999) an Internet-based administration is preferred to target individuals with chronic pain. A survey consisting of 25 close-ended questions was designed through Qualtrics, an Internet-based survey design instrument which allows researchers to customize surveys based on templates and tailor them to specific use (Qualtrics, 2015). Qualtrics also generates results and conveys them in descriptive statistics, graphs, and charts. Plus, all data are password protected and can be downloaded into a spreadsheet or database for future use. The economic advantage of designing and distributing the survey through Qualtrics, combined with the rapid turnaround in data collection makes this research design an appealing choice for me as a researcher. The ability to take the survey online, 24/7 from the comfort of one's couch, makes this research design appealing for the intended audience.

Fowler (1995) outlines strategies for creating good measurement of subjective questions which include answers that can be analyzed in a consistent way, that mean the same thing for all respondents, and provide meaningful information. To satisfy reliability, Creswell (2009) recommends that questions need to be understood consistently by all respondents. Both of these suggestions were implemented by designing the survey so that each question asks a single

dimension so only one response was elicited from respondents. To standardize the response task a continuum using a strongly agree to strongly disagree range, with a total of four options, was integrated. Since the survey inquires about perceptions of how respondents feel supported or understood by others, Fowler (1995) recommends offering a fifth "I don't know" response so respondents can indicate they are not familiar with their feelings on the topic. Some researchers claim offering a neutral position or "I don't know" choice is a practice of being socially conscious researchers while others say it allows respondents to avoid thinking and or committing themselves (Oppenheim, 1992). Rather than force respondents to answer the question and contribute to noise in the data, I prefer to offer respondents an "Other" option so they can provide a textual response to elaborate or clarify any response

In designing survey response options, the use of adjective responses over numeric categories is preferred as the points are more consistently calibrated by the use of words (Fowler, 1995). On a numeric scale there may be more ambiguity about the meaning of a neutral point, like 5 on a scale of 1-10. "Almost certainly, people are inconsistent in the way that they use middle parts of the 10-point scale" (Fowler, 1995, p.54). Further, I wanted to disassociate respondents from the 1-10 pain scale which they are routinely subjected to during a clinical office visit.

### **Survey Validity**

The survey instrument was developed after conducting two six-week online writing workshops. This survey tool is original work and has never been implemented before; therefore validity and reliability are limited.



## **Informed Consent**

The initial text of the survey detailed the aims of the survey, revealed my personal chronic pain identity and stated the purpose of the research: “to investigate if there is any therapeutic value in talking about pain.” The informed consent followed the initial overview and satisfied IRB protocols by acknowledge the voluntary nature of completing the survey and that respondents can stop taking the survey at any time, without penalty. Details pertaining to the length of the survey and expected time to complete the survey were also provided. My email address was provided for respondents to contact me if they had any comments or questions.

The first survey question asked respondents if they agreed to participate in the study. Skip logic enabled respondents answering "Yes" to move to the next question whereas respondents answering "No" were moved to the end of the survey where the following message appeared “We thank you for your time spent taking this survey. Your response has been recorded.”

## **Target Audience**

To confirm that this survey was reaching its intended audience of individuals with chronic pain, the second survey question asked respondents if they experience chronic pain. In this way, respondents had to self-identify as having chronic pain. Since this survey is aimed at better understanding the ways in which individuals with chronic pain talk about their pain, respondents who identify as having a concealed disability that is commonly stigmatized (Good, 1992; Jackson, 2005; Werner, Isaksen & Malterud, 2004) conveys their identification with a marginalized group. As Werner and Malterud (2003) contend the ways in which individuals with chronic pain perform their pain through discursive practices helps to construct their identity. More than delineating a clinically based sample of individuals with chronic pain, this research

seeks to solicit input from individuals who identify as having this pain. As Richards (2008) states, “the expert on the lived experience of disability or illness is not the clinician, but the person experiencing disability or illness” (p.1717).

The act of identification is a significant step as some people experience chronic pain, but don't identify as having chronic pain. Some may experience chronic pain but their presentation of symptoms does not match a clinical diagnosis so their experience may lack medical validation. Given the concealed and contested nature of pain (Johansson et al., 1996), individuals who identify as having pain and being a part of this chronic pain identity are the desired respondents to best understand communication practices.

Skip logic enabled respondents answering "Yes" to move to the next question whereas respondents answering "No" were moved to the end of the survey where the following message appeared “We thank you for your time spent taking this survey. Your response has been recorded.

The third survey question asked respondents if they had been diagnosed with a chronic pain condition. Again since the experience of chronic pain is the selection criteria over a clinical diagnosis, respondents who answered “No” were allowed to continue keeping the survey. The full survey tool is included as Appendix L.

### **Sampling Procedures**

The survey was cross-sectional in design, with data collected during a two week period beginning February 25 and ending March 13, 2015. Recruitment for survey respondents took on a clustering procedure where I first identified an already established group of chronic pain sufferers and then sampled from within the group (Creswell, 2009). Participants were recruited from chronic pain devoted social media websites hosted on Facebook, Reddit, and Twitter. All of

the Facebook sites were privately maintained by individuals, and not managed by organizations or non-profits. These sites were selected due to their intent to serve as educational and supportive outlets for people with chronic pain. From all of the chronic pain social media sites, only the sites with active posts and with followers exceeding 400 members were selected to increase the chances of survey completion from an engaged audience. Each member of one of these groups had an equal probability of completing the survey, making for a randomized sample. However, due to the nature of social media where the most current post sits at the top of the webpage, those members that logged in the first day the survey link was posted (Feb 25, 2015) were more likely to see it. Less active users or those that logged on days later had to scroll down the webpage to see the survey link.

To gain entrée into the online communities and build rapport, I strategically built up my online presence prior to survey dissemination, similar to the ways I did for the qualitative data collection. In December of 2014, I created Reddit and Twitter accounts using pseudonyms. I used my own personal Facebook account to show others users my authenticity as a woman who suffers from chronic pain when I asked to join the following Facebook pages: Chronic Pain Info, Chronic Pain Journal, Chronic Pain Self-Management, Chronic Pain Body and Soul Support Group.

While I amended my IRB form to allow for this survey design and sampling procedure and waited for its approval, I actively posted, liked, and commented on other members' posts. Once I received IRB approval, I posted the following post on the various Facebook pages:

*I need your help. I am a fellow chronic pain sufferer and am a PhD student at the University of North Dakota researching chronic pain communication preferences. I need your help to better understand how individuals with chronic pain talk about their pain. I would*

*greatly appreciate your participation! Please click on the link to complete the survey. Thanks in advance!*

[https://und.qualtrics.com/SE/?SID=SV\\_6rpSjvbxQUF28cZ](https://und.qualtrics.com/SE/?SID=SV_6rpSjvbxQUF28cZ)

I made a twitter post on February 26, 2015 including the following tags and using a wintry landscape picture to create visual appeal:

[#PhD](#) study [#communications](#) of [#ChronicPain](#) needs your input. [@PainResForum](#)

[@GivePainAVoice](#) [https://und.qualtrics.com/jfe/form/SV\\_6rpSjvbxQUF28cZ](https://und.qualtrics.com/jfe/form/SV_6rpSjvbxQUF28cZ) ...



Before I could post on Reddit, I had to let the moderators of the Chronic Pain group preview the survey. They approved of my research questions, but thought my demographic questions were invasive. They said I needed to acknowledge that respondents could skip questions. In the initial survey text, I added this statement: “This survey is voluntary and you may stop taking the survey at any time.”

I then sent the survey link again to the moderators and they approved it. I posted the following on March 3, 2015.

*I need your help. How do you talk about your pain? I am a PhD student at the University of North Dakota researching communication preferences. I would greatly appreciate your participation. Thanks in advance!*

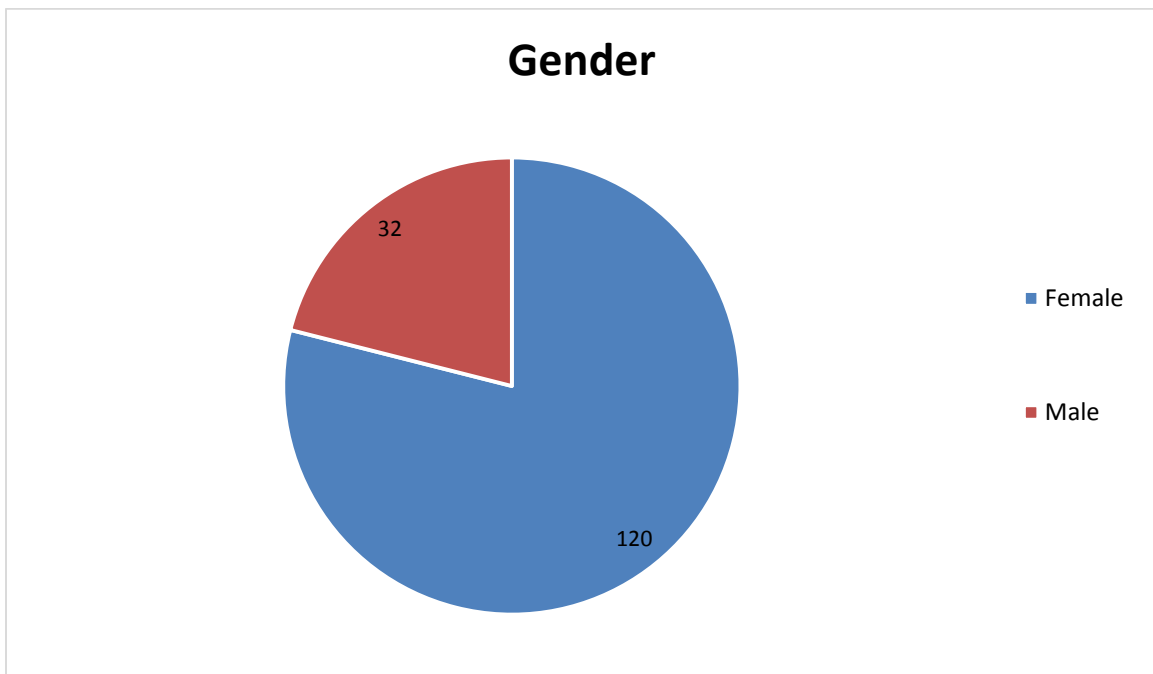
### **Survey Sample Size and Respondent Characteristics**

The total number of respondents to take the chronic pain communication practices survey was 192 (N=192) with 157 (N=157) completing it in its entirety, representing an 82% completion rate. However, completion rates vary for each question as respondents chose not to answer every question. Respondents represented a wide range of ages, educational levels, insurance providers and geographic locales. Of the 162 respondents indicating their gender, female respondents outnumbered male respondents at an almost 4:1 ratio with 127 females and 35 males indicating their gender. Overall, survey respondents were young in age. A majority of the 163 respondents completing this question were between 25-34 years of age (N=54). The next most frequent age bracket to be represented were those between 35-44 years of age (N=41), followed by those who were younger than 25 years old (N=25) and then those who were between 45-64 years of age (N=23). Of the 162 respondents indicating their race that best described them, the majority of respondents were White (N=145) and the next largest racial category was Asian, (N=3). Nine (N=9) respondents indicated other, and three (N=3) preferred not to answer.

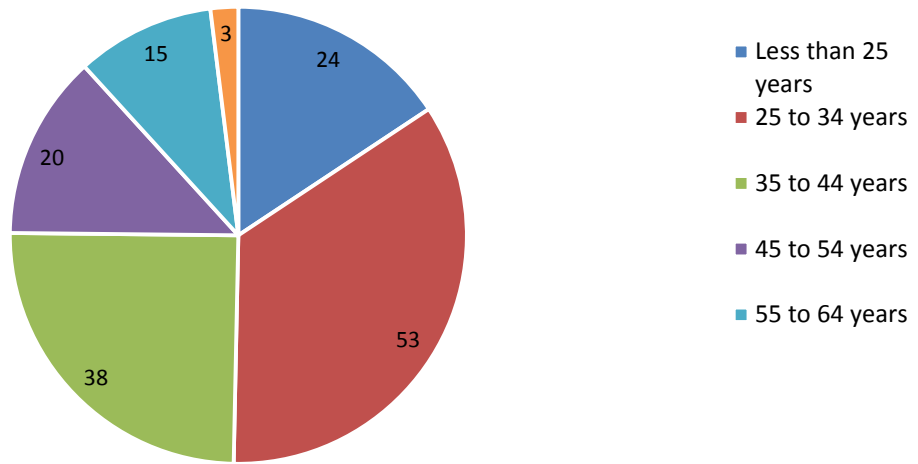
In terms of the highest level of education achieved, respondents represent an educated sample. Of the 163 respondents answering this question, a majority had some college (N=47); a plurality had a bachelor's degree (N=38) or masters, doctorate or professional degree (N=32). Out of the 163 respondents to indicate their insurance status, over 90% (N=152) of respondents had some type of insurance with insurance provided through one's employer being the most

common (N=60), followed by other types (N=32), and private insurance (N=28). Sixteen (N=16) respondents had Medicare and fifteen (N=15) had Medicaid.

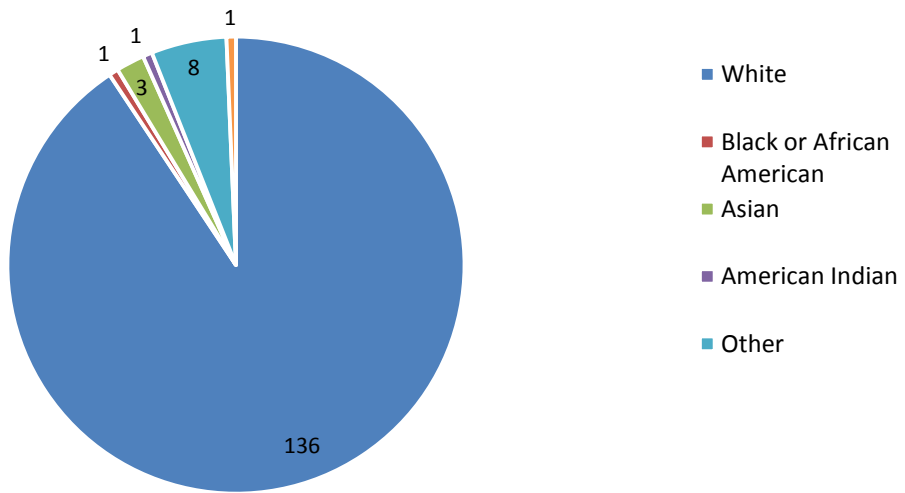
Survey respondents came from all over the world. One hundred forty nine respondents entered their geographic locale. Thirty-eight states in the United States were represented and eight countries were represented. Within the United States, a plurality of respondents came from California (N=12), Texas (N=7), and Florida, Illinois and North Dakota all had five respondents (N=5). Four respondents (N=4) came from each of the following states: Colorado, Indiana, Oregon, Virginia, Washington, Georgia and Pennsylvania each had three (N=3) respondents. Respondents provided a worldwide perspective with a plurality of respondents coming from Canada (N=16), United Kingdom (N=9), Australia (N=6), New Zealand (N=3) and one respondent each from the countries of Argentina, Denmark, Netherlands, and South Africa. A complete breakdown of respondent demographics are shown in Figure 5.

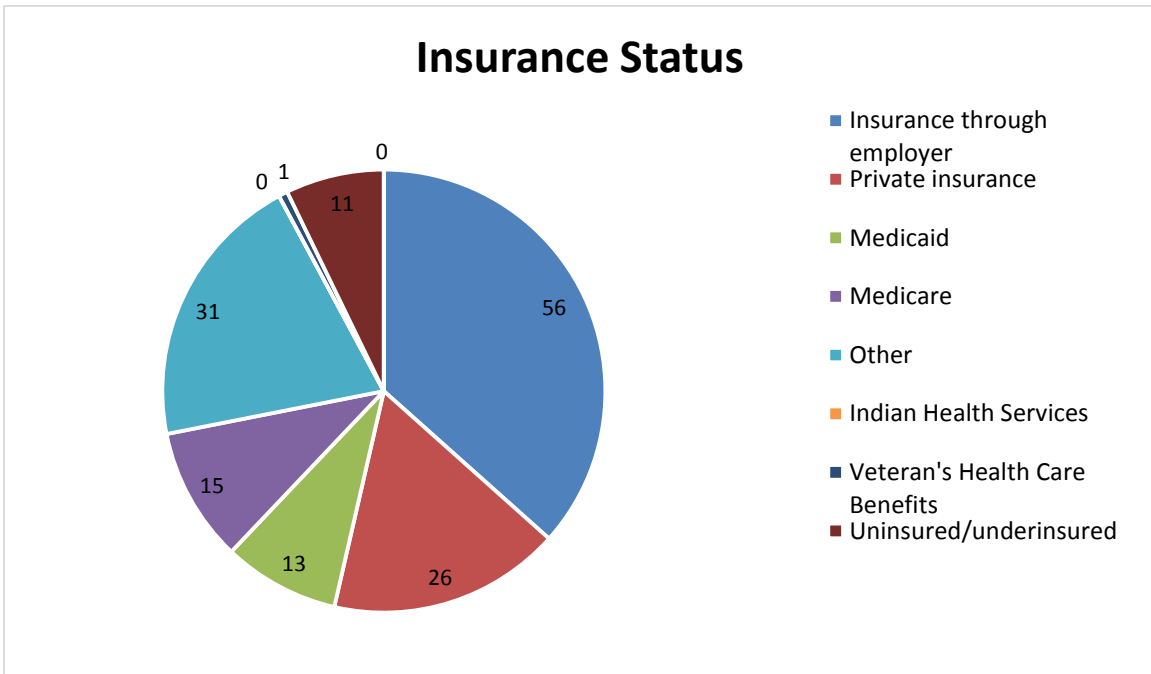
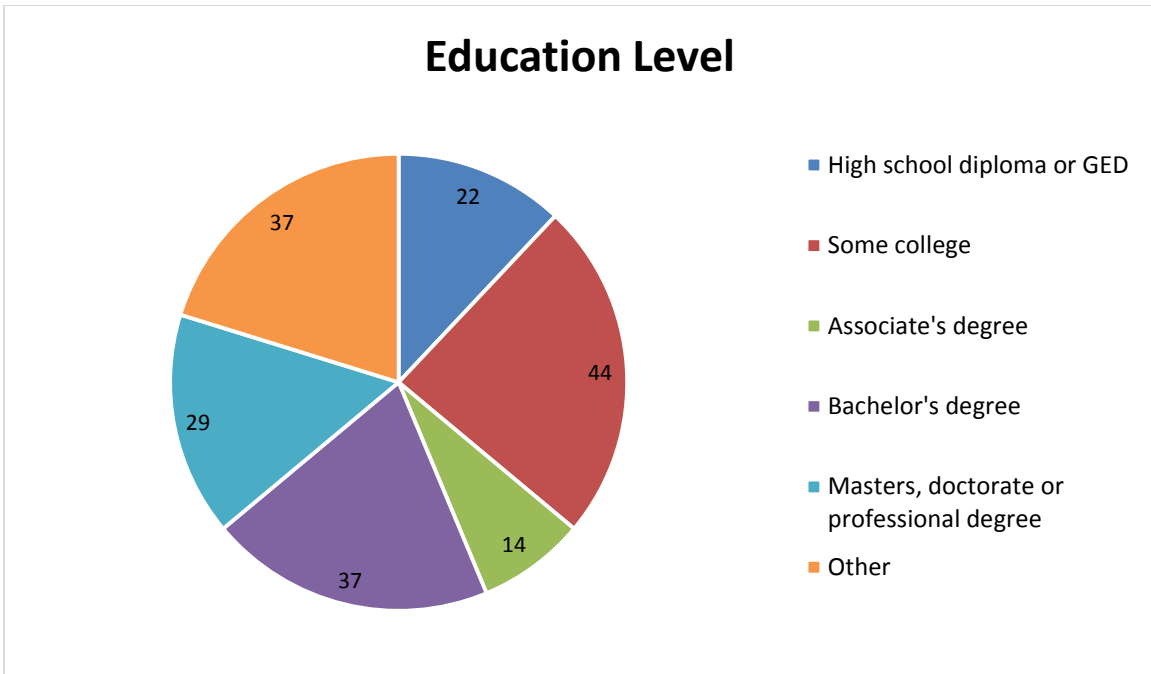


### Age



### Race





**Figure 5. Survey Respondent Demographics**



## **V: Phase Two: Quantitative Data Analysis**

To evaluate the survey, each survey question was analyzed using a narrative description alongside a visual depiction using a pie graph. Textual responses that respondents manually entered were analyzed using a thematic coding analysis to look for emerging patterns.

### **Statistical Tests**

To try to answer research questions three and four and determine whether the independent variable, gender, accounted for differences in the dependent variable, communication preferences, an independent samples t-test was conducted. T-tests assess whether the mean scores of two groups on the same variable are statistically different from one another (Treadwell, 2011). T-tests have been used in research involving chronic pain to help with patient pain assessment (Peppin, Marcum, & Kirsh, 2014); to examine genetic disposition for pain sensitivity (Diatchenko et al., 2004) and to study the use of mindfulness meditation to self-regulate chronic pain (Kabat-Zinn, Lipworth & Burney, 1985).

With gender serving as the independent variable, the t-test seeks to examine the statistical difference that gender has on the dependent variable, communication preferences. A statistical difference is determined by looking at the differences between mean scores of two groups relative to the range of scores for each group and each group's size (Treadwell, 2011). When calculating the formula for a t-test, the top part is the difference between the means; the bottom part is the standard error of the difference, which is computed by taking the variance for each group and dividing it by the number of people in that group (Trochim, 2006). A positive t-value indicates the first mean is larger than the second. The alpha level was set at .05, consistent with the rule of thumb in social science research (Trochim, 2006).

## **CHAPTER FOUR**

### **RESULTS**

Results from both the qualitative and quantitative findings are reported and then synthesized in an attempt to answer the research questions and triangulate findings. In this sequential, exploratory mixed methods research design, the qualitative findings were used to inform the quantitative design so the qualitative data will be presented first, however the themes generated in the discourse analysis correlate with the survey data. Part one of this chapter starts with presenting the qualitative data which features extensive quotes to illustrate the categorization of the interpretive repertoires. Part two presents survey respondent characteristics and survey data as a means to answer the research questions.

#### **I: Qualitative Results**

##### **Discourse Analysis of Writing Workshop Responses**

Participant responses posted to the online writing workshop varied in length from four to five sentences to eight to ten paragraphs, but typical responses were several paragraphs. To facilitate the analysis, data was entered into NVIVO software to run various queries and examine word frequency. The word count for both workshops is 23,675 words. A word frequency query yielding the words with the highest frequency were pain (N=547; 4.79%), know (N=69; .60%) time (N=68; .60%), feel/feels (N=58; .61%), life (50; .44%), days (N=49; .43%), want (N=49; .43%).

Results from the discourse analysis of the responses posted to the online writing workshop revealed four interpretive repertoires that participants used to construct their experience living with chronic pain. Word clouds were also generated in NVIVO that helped to visually show the associations between words and their synonyms in tangential relationships and were integral in the development of the interpretive repertoires. Word clouds are included in Appendix N.

Discourse analysis emphasizes the way language is used to construct meaning (Cheek, 2000) and sheds light on how individuals with chronic pain make meaning of their experience of living with pain. The resulting repertoires emerged by looking at the responses posted to the writing workshop not only on the level of the word or sentence, but also on the context (Bhatia, Flowerdew & Jones, 2008). Overall, the non-medical context in which these responses were posted plays a large influence on the discourse. Posts were written casually, with frequent use of contractions and shorthand abbreviations (e.g. 3x instead of writing out three times). Sentence fragments and misspellings were common, which may not denote poor grammar but be indicative of a loose, conversational style. Some posts were written in a stream of consciousness style, with staccato words grouped together by ellipses. For example, “low pain days...happy as a lark, focused, ready to conquer, sparkle, sparkle, sparkle...flare days...crabby, sad, introverted.” Capitalizing words in the middle of sentences was commonly used to note emphasis as well as other stylistic features like dashes and punctuation to denote smiley faces (☺).

The casual tone to the writing reflected the informal atmosphere of the online writing workshop. This communication style is different from the communication exchanges that occur between providers and patients in a clinical setting where the biomedical model sets the agenda (Beck, Daughtridge, Sloane, 2002) and positions patients with chronic pain in a demoted status

where they are viewed as helpless and unreliable sources of knowledge about their body (Jackson, 2005; Vanderford, Jenks & Sharf, 1997). Discourse analysis helped to place priority on the system of meanings individuals with chronic pain make regarding their pain. Outside of medical contexts and absent power levels where meaning is tied up in scientific discourses that constitute and regulate patients, the writing workshop participants were all on equal footing and this parity allowed for candid conversations.

Moreover, the relaxed environment enabled participants to share deeply personal information. Participants voluntarily revealed intimate information about their own pain conditions as well as discussed marital and familial relationships. This level of intimacy indicated a level of trust and rapport participants had with one another. Even though personal identity was anonymous and protected with screen names, the confidentiality of the online writing workshop enabled participants to feel safe to disclose private and personal information. The qualifying condition that all participants had some sort of chronic pain unified the group and this commonality allowed high levels of disclosure. The extent of disclosure among participants revealed a familiarity that cannot be attributed to knowing each other, given the anonymity, but attributed to the familiarity of living with chronic pain.

### **Developing Interpretive Repertoires**

The vocabularies participants used invoked various identities. The interpretive repertoires were inter-changeable and sometimes contradictory. For example, the repertoire of ‘pain as discredited self,’ where the broad conceptualization was the struggle participants had to validate their invisible pain, was vastly different than the repertoire of ‘pain as teacher,’ where participants reflected on lessons they learned from living with chronic pain. However, by changing the repertoire according to the situation, participants were able to adjust their

framework. In the ‘pain as discredited self repertoire’, participants discussed the extent of skepticism and invalidation they received from others and the efforts they underwent to conceal their pain. This discourse presented pain sufferers as victims of disbelief and showed how that doubt has shaped their identity as well as their pain communication practices. Alternately, in the ‘pain as teacher’ repertoire participants constructed their identity as wise and experienced pain sufferers who were able to reflect on their experience and impart knowledge to others. This discourse presented participants as empowered pain advocates.

Weedon (1987) claimed language is the place in which our sense of selves, our subjectivity, is constructed. McConnell-Ginet (1980) added that the way we describe, define and classify things conveys important social, cultural and historical information about the people who use it and there is much power in the selection of words and construction of sentences. Therefore, to lend power to the individuals who participated in the writing workshop, as they are the experts on their own pain, the following repertoires contain numerous narrative extracts to hear from them using language that is their own.

Starting with a bird’s eye view of how individual sentences from the writing workshop were grouped into thematic categories and then how the thematic categories were classified into the four interpretive repertoires, Figure 6 visually illustrates the conceptual map of the qualitative analysis. A closer examination of coding schemes within each interpretive repertoire are displayed in Figure 7. Following the visual depictions, the four interpretive repertoires are presented with a discussion succeeding each section to explore the posts within the larger context of the experience of living with chronic pain.

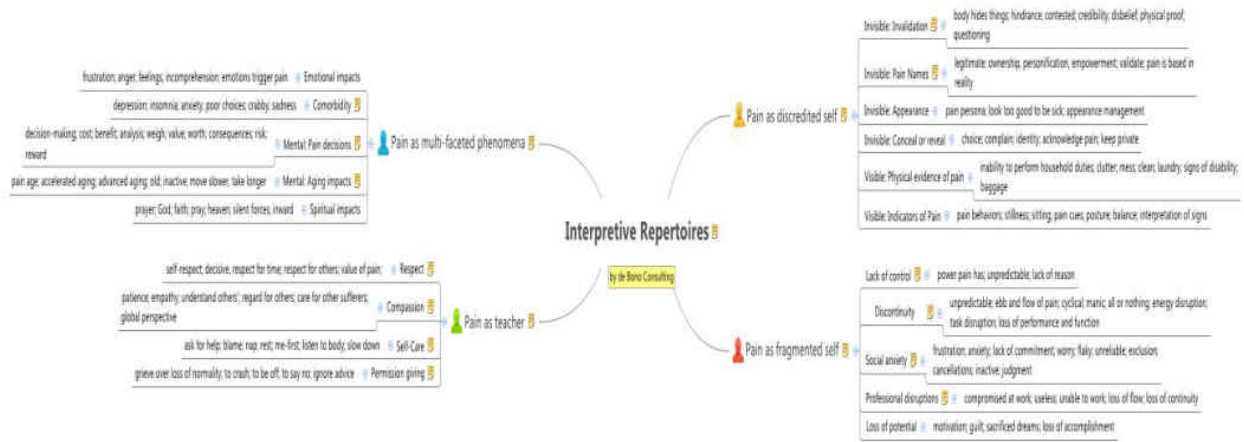
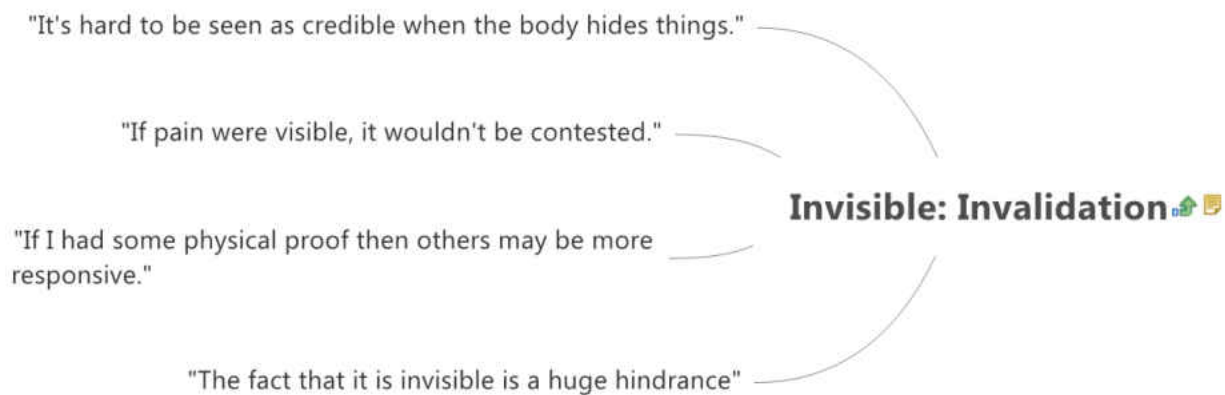


Figure 6. Conceptual Diagram of Interpretive Repertoires

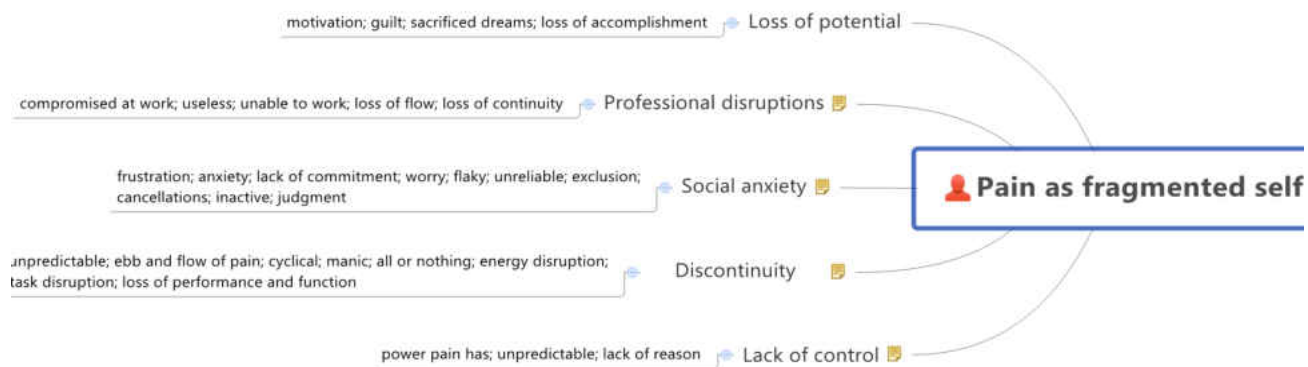
Figure 7. Breakdown of Individual Repertoires



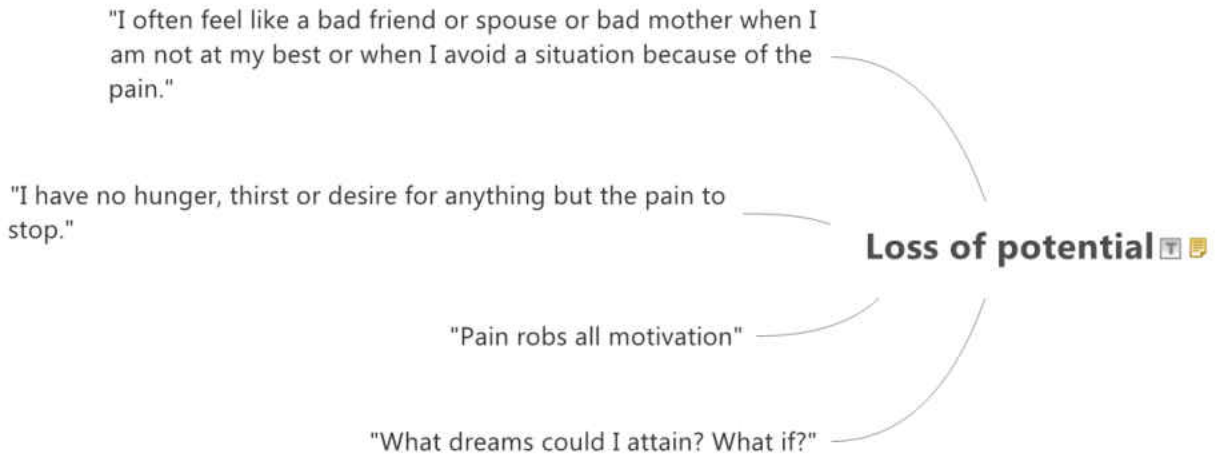
## 1. Pain as discredited self coding scheme



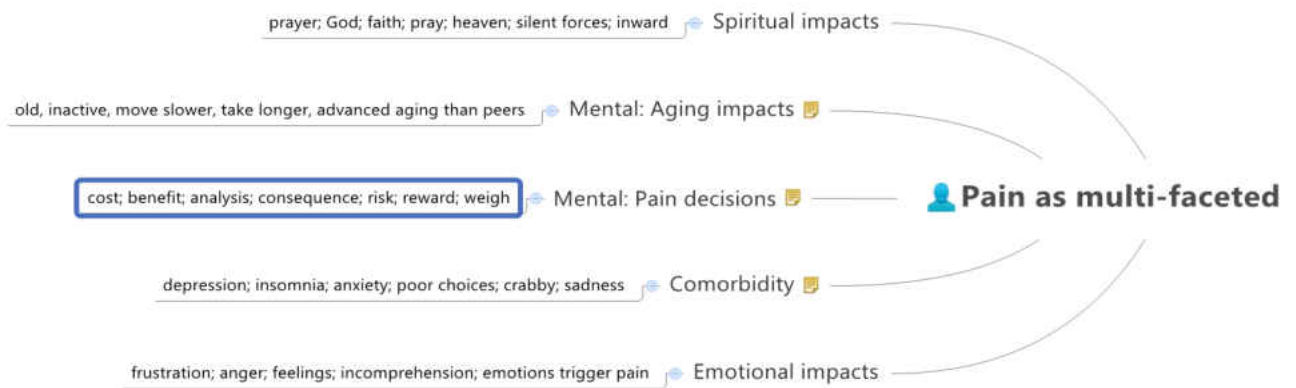
### 1a. Example of data for coding scheme



### 2. Pain as fragmented self coding scheme

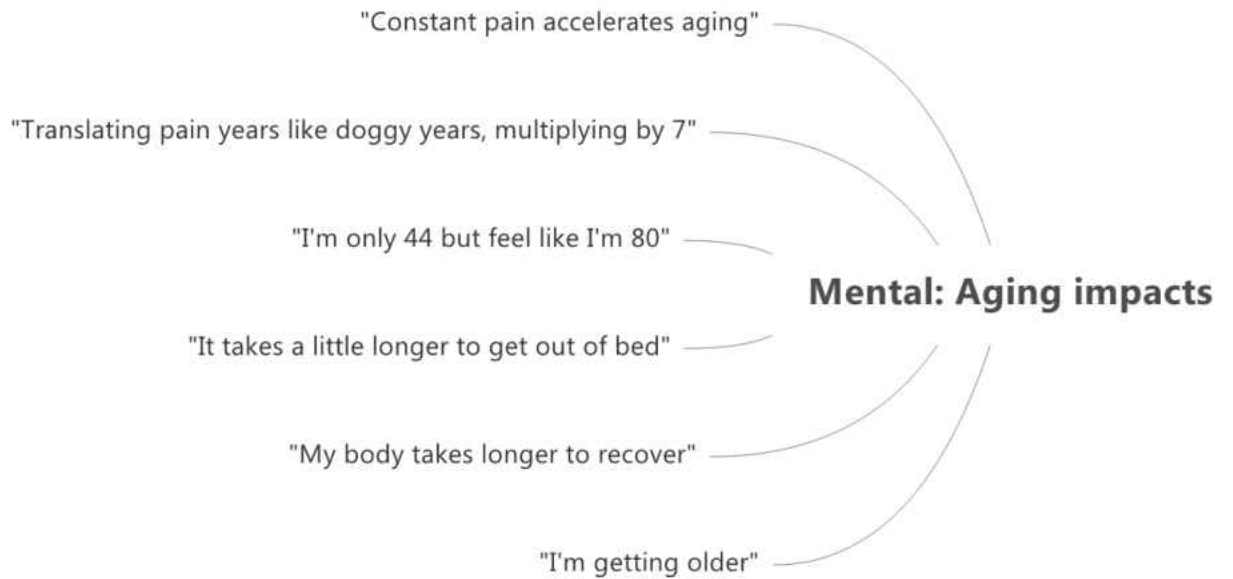


## 2a. Example of data for coding scheme

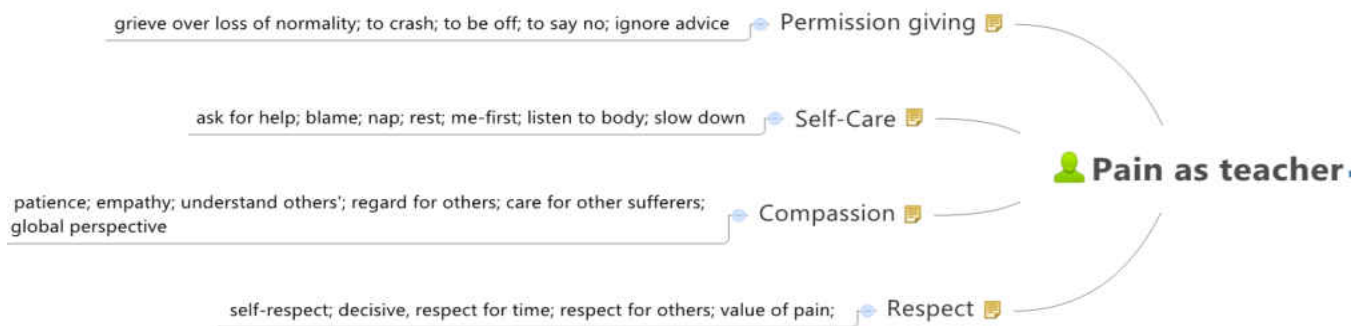


## 3. Pain as multi-faceted self coding scheme

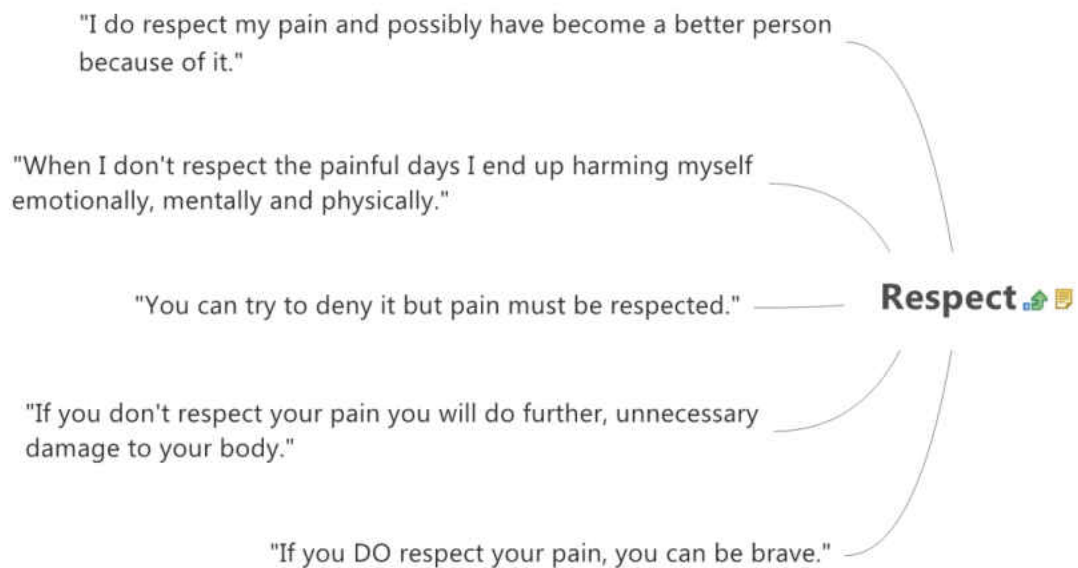




### 3a. Example of data for coding scheme



### 4. Pain as teacher coding scheme



#### 4a. Example of data for coding scheme

##### Relationships Between Interpretive Repertoires

While this overview of the interpretive repertoires depicts the thematic analysis within each repertoire, there is some overlap within the repertoires. While the Pain as Discredited Self and Pain as Teacher repertoires are mutually exclusive, meaning the themes generated within are discrete categories, the other two repertoires share a large intersection. Themes within the Pain as Fragmented Self repertoire contribute to the Pain as Multi-faceted Phenomena repertoire and vice versa. The nature of their relationship is not linear but circular where impacts and influences are not confined to one direction but radiate outward creating multiple impacts. Figure 8 portrays the interrelated relationship between these two repertoires where the purple diamonds represent the repertoires, the green circles represent thematic categories within the repertoires, and blue

ovals represent particular examples of that coding scheme within the theme. The graphic displays the extent of connection between these themes where the motion is cyclical; the arrows show how one theme contributes to numerous other themes. This graphic representation helps to convey the complexity of living with chronic pain and charts the interrelated impacts that defy singular classification.

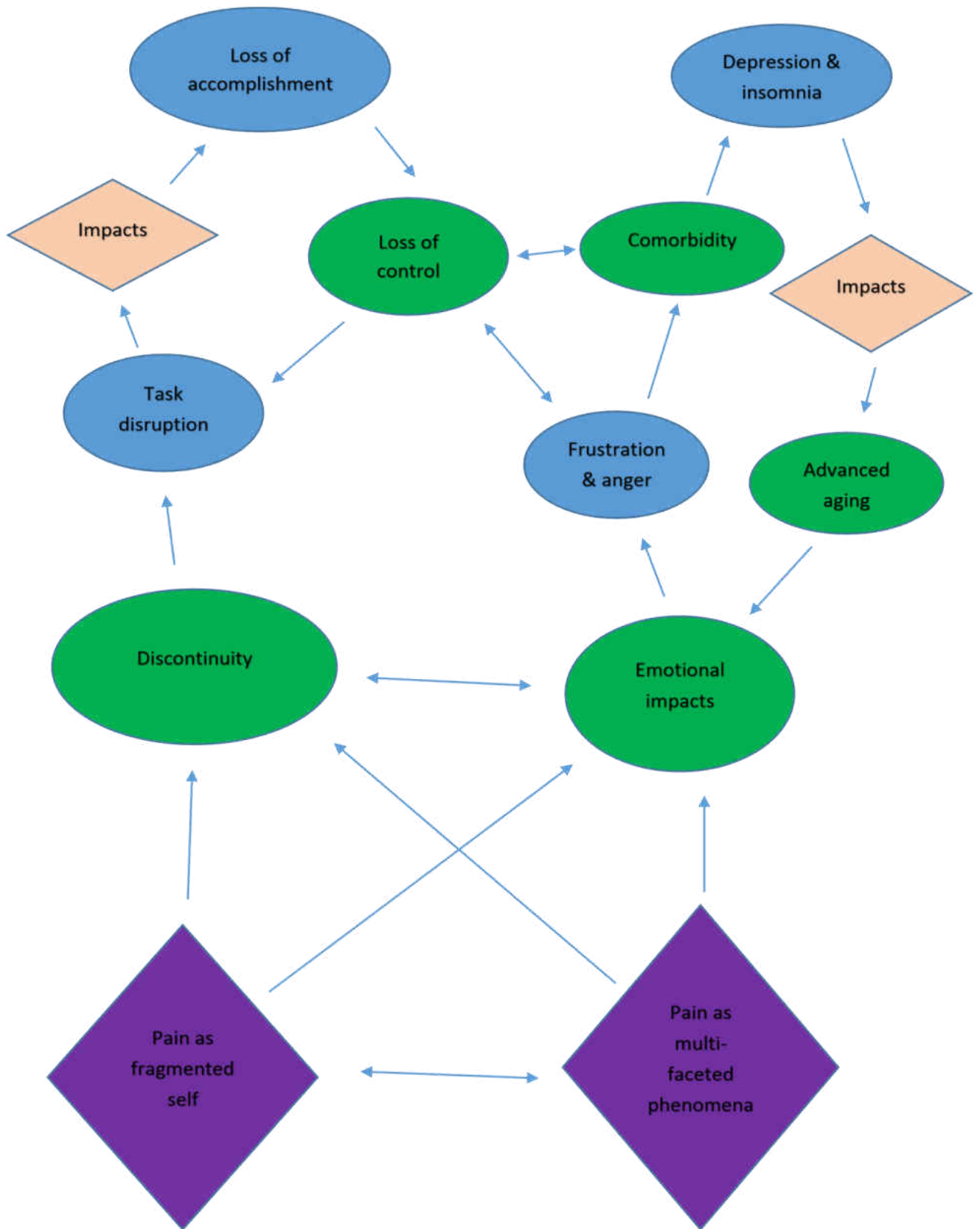


Figure 8. Relationships Between Interpretive Repertoires

## **Interpretive Repertoires**

### **1. Pain as Discredited Self**

Posts pertaining to the struggle for credibility are illustrated in this repertoire and include both the hindrance of pain's invisible nature as well as the visible ways pain manifests in participants' daily activities and home environs. The ability of pain to be physically exhibited explores the dichotomy of pain being invisible and visible at the same time.

Pain's invisible nature was perceived as a great barrier to participants' credibility as a knowing subject of their pain, yet it also yielded them to have more control about how and with whom they disclosed their pain.

#### **A1. Invisible: Invalidation**

The invisibility of pain caused participants to receive much questioning and disbelief. For example, participants shared how pain affected their moods in an outward display, but others may not know the cause of the mood change was due to pain. Participants wrote that:

- "Pain's disguise is its own enemy"
- "I have seen doctors, chiropractors, massage therapists, etc. Many of these have shook their heads and questioned me as to my knowledge of real pain."
- "If pain were visible, it wouldn't be contested; my doctor would better know how to manage it and my sister would know I'm not making it up."
- "If I had some physical proof then others may be more responsive, compassionate, and empathetic."
- "It's so hard to be seen as credible when the body hides things."

- “The fact that it is invisible is a huge hindrance which I also feel causes me to be negative sometimes and I just don’t like it because my friends and family know I am normally a happy-go-lucky kind of gal.”

## **Discussion**

As a discourse, these posts convey the concept of script in which participants construct events where the routine character of the described events imply they are features of some larger, approved or disapproved, pattern (Silverman, 2011). The repeated use of the conditional “if” or the alternate “that fact that...causes me to...” shows a routine characteristic that the experience of chronic pain is hinged on a logic statement; if X then Y. In this case, if participants had some visible proof of pain, then they would be deemed credible. Since they don’t have this proof, their logic is reasoned faulty. The way these statements regarding pain’s invisible nature sheds light on the way participants attend to the normative character of their actions to gain credibility.

### **A2. Invisible: Pain Names**

The lack of visibility and subsequent credibility caused some participants to create their own names for their pain. The ability to have a name for their pain helped to legitimize their experiences and move them from the mental (it’s all in your head) to the physical, from an internal to an external reality. Participants shared their creative strategies to offset their invalidation by naming their own pain.

By using personification participants were able to objectively talk about their pain and add a sense of comedy to their writing. One participant named her pain “Natalie” and this direct address enabled the writer to acknowledge the impact Natalie has on her life. In this way, naming pain can be an empowering act. When sufferers select the name for their own pain, there is a sense of ownership and acceptance of the pain.

- “Without my permission, Natalie takes possession of everything she wants. I have no choice but to tolerate all her misbehavior. If I force her to leave, I risk death.”
- “In defense, Second Toe has grown a super-thick nail that has to be trimmed with a tool made for trimming horse hooves.”
- “Pain has taken over my body like a bad roommate. After years of trying to evict her, I’ve learned that there’s no getting rid of her.”
- [My pain is an] “angry bedmate who wishes to rob me of every wink of sleep.”
- “I am married to it without the option of divorce.”

A name for pain can also validate the subjective experience and help to foster a sense of community of individual pain sufferers with others who share the same condition.

- “It’s funny that the name doesn’t make the pain go away, but sometimes, the name for a pain is more powerful since it makes it more real. My pain has a name. It’s based in reality and at least someone else has had it. It makes me feel a little less isolated and weird.”
- “With the way the medical profession minimizes the effect of pain or the importance of treating it, I appreciate there are some people who recognize it as ‘real’ and somehow ‘knowable’.
- “I suppose validating the pain also validates me.”

One participant wrote that when she complained that her skin hurt to her doctor, he asked her how it could hurt when it’s intact. He dismissed her complaints. Later, she researched it in a *Scientific American Magazine* and found a name for it—allodynia, which is a condition that occurs when chronic pain is untreated. She wrote, “I found that information comforting because it let me know my sensation of pain is based in reality.”

## Discussion

Participants' posts reinforced the difficulty they have in trying to gain validation for their invisible pain and reiterate the tendency for female patients' to have their accounts of pain dismissed, belittled, attributed to psychosis or stress that has been documented in previous studies (Ford, 1995, Asbring & Narvanen, 2001; Werner, Isaksen & Malterud, 2004). Absent a name or diagnosis for their pain women often struggle for the maintenance of self-esteem and dignity at the risk of being shamed and disempowered, both as women and as patients (Werner & Malterud, 2003).

The numerous posts which document the ways participants worked to counter the invisibility of pain by naming it and making it visible conveys the need they have to confirm their pain. Having a name for pain can be validating for the sufferer on three accounts. First, by confirming that the invisible sensation they are experiencing is real they are endorsing Belenky et al.'s (1986) argument that one's own bodily constructed experience counts as objective knowledge. Secondly, naming pain brings about recognition of it. The name plants it firmly in reality and grants credibility to the sufferer. As Birk (2013) discusses, credibility is at the heart of the chronic pain experience. Moreover, as Marcus and Simon (2006) state, finding a label that fits one's condition can provide meaning, offer emotional respite, grant recognition and foster a sense of empowerment to the sufferer. In *Disability Theory*, Tobin Siebers (2008) discusses the subjectivity of pain, examining both how the notions of pain and individuality must be communicable as subjects. He says "Individuality derived from the incommunicability of pain easily enforces a myth of hyperindividuality, a sense that each individual is locked into solitary confinement where suffering is the only object of contemplation" (p. 43). Having a name for



pain, whether diagnosed by the medical community or created by the individual, helps to alleviate the hyperindividuality that Siebers (2008) discusses.

Thirdly, naming pain makes pain visible. The name serves as a bridge, connecting sufferers and lessening the effects of marginalization that accompany a stigmatized condition such as chronic pain (Jackson, 2005; Holloway, Sofaer-Bennett, & Walker, 2007; Werner, Isaksen & Malterud, 2004). A name for pain is empowering. Learning of a name can normalize the individual, connecting them to the real world and with others who also share this same pain phenomenon. In this way, identifying pain can be seen not as a diagnosis but as a tool of connection. While participating in a naming ceremony may not minimize their pain, it may help individuals with chronic pain talk about their pain and bring it into reality. It has a name; therefore it exists. The scripted act of naming pain conveys the intimacy with which individuals with chronic pain know their pain and may help to demystify it.

### **A3. Invisible: Appearance**

Another discourse within the discredited self repertoire was the extent participants tried to conceal their pain in order to fit in. In this way, the impacts of pain were minimized so participants could ‘pass’ as able-bodied (Joachim & Acorn, 2000). The idea that participants may look too good to be in pain affirms what Hadjistavropoulos, McMurty and Craig (1996) discussed when they concluded that perceptions of women’s appearance influences health care providers’ assessment of pain. The following statements convey the contradiction of how physical looks can impede pain communication.

- “My mother always told me that I look so good always that no one ever knows the pain you are going through each day. I seldom mention my pain to anyone.”

- “One time I was in terrible pain and needed to go to urgent care. I could barely breathe and was having a panic attack because my pain was so intense. The guy sitting next to me on the bus asked me where I was headed. When I told him the clinic he said, ‘but you don’t look like you’re in pain.’ I wanted to punch him. What did he know about how my pain looked?”
- “I learned that playing the role of pain has certain advantages...like getting attention from doctors but otherwise I try not to show my pain.”
- “Others have no idea the extent we go to in order to maintain normalcy.”
- “I always thought [of others’ chronic pain] suck it up. You are smiling and laughing. It can’t be that bad. It however can be THAT bad. You have to smile and laugh because you don’t want to go through life completely miserable.”

### **Discussion**

These statements allude to cultural perceptions of what people in pain look like and suggest that attractive physical appearance seems to act as a deterrent to pain communication. The interpretation that pain grimaces and pain expressions may be confused for calling attention to oneself may be associated with the cultural norm prevalent in Scandinavian culture which discourages individuals from drawing attention to themselves. A pain sufferer’s positive regard may discourage others from asking about her health and prohibits her from bringing it up. The idea of playing the part of pain sufferer coincides with Jackson’s (2005) notion of pain as a performance where it is an act that must be performed in order to be believed.

#### **A4. Invisible: Conceal or Reveal**

Alternately, pain’s invisibility presented sufferers with a choice. Absent any physical reality, individuals could determine how much and with whom they want to share it or keep it

hidden. The choice to conceal or reveal their pain was theirs. Chronic pain grants its sufferers a sense of control that other disabilities do not. Participants shared how they are very conscious about with whom they share their pain identity with, how they broker pain disclosures, and how they navigate the “big sympathy” they receive from others.

Participants expressed fear that if they complain too much about their pain, yet maintain their normal routine, then there was a disconnect with friends—the two actions did not match up: pain and functionality. In a way, there was a credibility gap, not because others disbelieved them but because of the incongruity of indicators of pain and high level functioning. On the other hand, if participants downplayed their pain and said “they are fine”, friends and family knew they were lying. Yet, there was a perception that others do not want a full explanation of their pain. There was a sentiment that pain details are “too much information.” Hence there was a catch-22 for credibility. Their trustworthiness was questioned if they spoke truthfully and seemed to be operating with normalcy yet questioned if they downplayed their pain. This double-sided conundrum played a large part in social interactions as individuals with chronic pain have to negotiate how much of their pain to disclose and to whom.

- “I would rather control my pain in the ways I have learned, than to tell others about it.”
- “I don’t want the fact of my constant pain to define my entire self, I’d like to feel I can refer to it freely when it’s relevant.”
- “I don’t want to be identified as Pain Woman. It’s part of me, but it’s not the totality of me.”
- “I also believe if you want your pain to be your disability, it will be. I have chosen to not take this path.”

- “Only those on a need-to-know basis even know about my chronic pain.”
- “I typically keep it [pain] to myself, close family and friends. I do not want anyone to pity me.”
- “One reason I acknowledge my pain so sparingly is I don’t want to feel as if I need to take care of them when they freak out about me.”
- “I’m glad the choice is mine to reveal or conceal my pain. To tell others or keep it private.”

## **Discussion**

While much research has been devoted to the amount of stigma that is associated with a concealed disability such as chronic pain (Pachankis. 2007), these findings convey a different tenor to the ability to conceal, emphasizing the sense of control and agency a sufferer has to conceal or reveal their pain. Bouton (2013) noted in her research that the choice to reveal one’s chronic pain identity can bring about the potential for community and empathy, yet participants may purposely exercise their control and choose not to communicate about their pain. The invisible nature of pain is positioned as an advantage in this interpretative repertoire as it allows participants to choose which identity to present, depending on context. Within this discredited self repertoire, the visible/invisible binary of pain is both a blessing and a curse.

### **B1. Visible: Physical Evidence of Pain**

Participants described the visibility of pain in terms of the impact it had on their inability to perform previous functions they could when they were pain-free. In this way, pain manifested itself outside of the body. For example, participants wrote about the inability to keep up with household duties due to their chronic pain. Pain took on the form of clutter as a visible reminder of all the day-to-day tasks that were not getting done. Their messy environments were indicators

of how much and how long pain impacted them. Unable to keep up with household chores, paying bills, or caring for pets, the physical clutter represented the extent of their disability, serving as a reminder of all that they were not keeping up with. The inability to perform household duties also was a source of anxiety as the dust and laundry piled up.

- “When my house is a mess it conveys how sick I am. It is a bold confrontation of my illness and inability.”
- “The clutter seems to magnify my migraines.”
- “My husband tells me, ‘I can tell you don’t feel well, the clutter is thickening.’”
- “My preferences for a tidy home are sometimes affected by the chronic pain.”
- “When I see the clutter, when I know there is laundry to do and bills to pay, it is all a huge drag to think about because I know the reason I am behind on it is because I had a weekend of pain and needed to sleep.”
- “Clutter is the closest reality to pain.”
- “If I am not doing laundry, check on me often. I don’t want it to get stacked up so much that I get overwhelmed the next time I am able to.”
- “If someone was willing to minister to me in my pain here is what it would look like: relief from house duties that hurt me.”
- “My husband has not picked up how I need to have help with the house, etc. This does stress me out and only increases the pain. Again, I hate to complain....”

Additionally there was a link between pain and clutter where the amount of clutter increased participants’ pain. The association between a clean house and clean mental space was applied to the realm of pain in that a clean and organized physical space enabled pain sufferers the ability to focus on healing rather than fret about all that needs to be done. Since pain is

something that is outside their realm of control, directing their desire for control on their physical surrounding takes on new importance. As one participant urged her family members to consider "cleaning the house as an investment in my health. It allows me to focus my energy on restoring myself rather than on picking up." This association with pain and clutter was reiterated when respondents indicated that the primary request for help came in the form of household chores. Respondents preferred help with household cleaning and pet care more than self-care.

While the correlation between the evidence of pain manifesting in physical realms pertaining to domestic chores is abundantly noted, it may be indicative of the homogenous participant sample. Since all participants in the writing workshop are women, they may have a larger part in household maintenance and prioritize household order and cleanliness more so than men. Further research is needed to determine if the focus on household clutter and mess is unique to women or if men with chronic pain experience the same aggravation.

Another way pain was revealed visibly was in the amount of physical accoutrements needed to treat the pain. One participant wrote "One way I've noticed pain's impact on me is the amount of baggage I need. I used to pack a duffel bag for a weekend trip or a little carry-on for the airplane, but now I need to check a bag full of medicine, ice packs, heating pads, special pillows, salves, lotions, balms, oils." This statement illustrates the physical evidence of pain in an indirect way and highlights the tangible impacts of living with chronic pain.

## **Discussion**

In the biomedical model, the body is the subject under scrutiny as medical professionals examine it in search for evidence (Morris, 1998). However, posts in this repertoire illustrate that the efforts to scan the interiority of the body may be misguided as it is the external environs that

produce the physical signs of pain. Rather than look within the body for signs of pain, these findings indicate that external surroundings implicate pain.

The shift away from the body as the source of pain and to the individual's environment as an indication of pain has profound implications for the field of pain. It deprioritizes the corporeal body and relinquishes the sufferer from having to reproduce pain. The idea of looking within a patient's home environment, rather than a person's body, to better understand their pain is an intriguing idea to consider. A person-in-environment perspective may shed light on the way pain impacts a person's functionality by taking into consideration the simultaneous and multiple interactions that occur between a person and her physical context. Personal living environments may closely indicate the extent of pain more so than one's body and assessing one's functionality may help to assess pain more so than pain scales.

By steering the focus of pain communication away from the body which may or may not reveal pain, and directing it to the home may reveal the extent of pain the person suffers as well as places for which support and help are needed. As one participant wrote, "Consider all of the effort you do to help me out as investments into my health. They are not chores, tasks, or favors. They are restoring or maintaining my health, my livelihood, my independence, my esteem."

By offering support for the loss of or impaired functionality due to pain, the definition of what constitutes therapeutic care may be extended from the body to encompass the home. In this way, supportive tasks and chores that aid a pain sufferer's environment may be regarded just as essential as medications that aid a sufferer's body. By broadening the idea of pain management to encompass one's external environment a more holistic perspective of pain is taken. This finding may have implications for health care providers to change the way they operationalize

the construct of physical pain. Additional questions on patient intake forms for assessing pain may include questions investigating the impacts of daily activities, relationships, work responsibilities and personal goals. These questions can coincide with numeric pain rating scales, but the inclusion of other impacts takes into account the multi-dimension aspect of chronic pain which may help providers may better understand the debilitating effects of chronic pain, and provide patients with a way to convey the indirect affects, thus gaining emotional support. Moreover, inquiring about physical abilities (or inabilities) and household chores that are not getting done may help facilitate pain communication as individuals with pain are focusing on concrete things and visible evidence of pain.

## **B2. Visible: Indicators of pain**

A number of participants wrote about the association between pain and sitting or stillness. In this case, the absence of movement was the visible manifestation of pain. Rather than sitting associated as a sign of relaxation, it was seen as an indicator of pain.

- “You know I’m in pain if I’m sitting still. Normally, I’m always doing something: sitting on the floor playing with my kids, cooking and doing the dishes; sweeping the floor, yard work, organizing schoolwork—always on my feet. In pain, I lay on the couch with an ice pack. I am still.”
- “When I’m in more pain than usual, I sit in my recliner all day and all evening.”
- “I have learned to do what is necessary around the house and take the time to sit and rest often.”
- “If I’m driving [in pain] I start sitting up straight and forward holding the steering wheel to my chest.”



- “House work, vacuuming etc is a KILLER, but it has to be done. I usually do a little bit at a time, sit and rest, do some more, sit, etc.”
- “When in pain I like to be kept in company not left alone...where I can sit and be still.”
- “My pain plans include doing the necessary jobs around the house, sit and rest, and begin again—and sit and rest again! I love to sit with soft music in a comfortable chair!
- “When I’m sick I don’t have full vision. I only see a very small world that consists of necessity. I know I’m starting to feel better when I notice dirt. It showed me the extent of how clouded my vision gets when I’m in pain”

Interpreting the behavior is critical as the external appearance of someone sitting does not denote pain. However, to those that know the sufferer well, they can decode the sitting behavior as pain behavior. The key to interpretation is hinged on disclosure as others need to know of the pain condition to know the behavior is abnormal. For example, one participant who had not shared her pain condition with her friends wrote that when her friends called and asked what she was up to, she said she was having a slow day and reading. Her friends, not knowing how to interpret these cues, responded by saying, “That sounds wonderful! I’d love to have a day like that.” The participant commented, “I wanted to say, ‘Well, I would love to have a busy productive day.’ But I don’t. I haven’t figured out how to have that conversation.”

This post exemplifies the misinterpretation of messages and behavior that is associated with pain’s invisibility. While there are visible manifestations of the pain, it takes a close reading of the context and by persons close to the sufferer to decipher pain’s impacts. Participants shared the need for education so that loved ones could pick up on their pain cues. As one participant

wrote, “One of my boys is very sensitive but the others aren’t bothered by it and haven’t picked up on my pain.” Others wrote of the role siblings can play in teaching other family members the pain cues as noted in the following post: “One of my boys gives me a back rub. Even though he is little and applies little pressure, it takes seeing this that others in the house know that I’m in pain.” Here communication is taking place non-verbally where the action of performing a back rub serves as the indicator of pain. Other examples of statements regarding pain’s visibility include:

- “If I am having spine pain...that is the worst as it affects all of my posture and movement.”
- “I must walk slower and my balance is off.”
- “My oldest is 11 and she understands a certain look on my face that indicates to her that I’m in a lot of pain or have had a rough day with managing the pain.”
- “I was totally unaware of the way pain affects my posture until a coworker asked me why I was walking funny. I thought I was doing a good job of masking my pain. She imitated me and showed how I was walking while leaning to one side.”
- “My daughter pointed out that when I’m in severe pain, I braid my hair and hold my face a certain way. She calls it my Viking mode as if I’m a warrior preparing for battle. I never knew I did this.”

Indicators of pain often come in physical forms but it takes a discernable eye to notice them. The ability to note changes in posture, movement, behavior is most likely to be perceived by those who know the sufferer well. These findings give testament to the role that family and friends play in the supportive network.

## **Discussion**

These posts show the varying degrees of awareness chronic pain sufferers have of the way their pain is manifested. The fact that indicators of pain are most often observed by children or coworkers, those that have close relationships to the pain sufferer, highlights the need for a support network to function as a mirror. By observing or imitating the pain behavior, they are acknowledging the person in pain; in a sense, they are validating the sufferer by communicating I see you and I see your pain. Since pain sufferers may not be aware of their non-verbal communication, there is need to teach their support network the necessity to attend to non-verbal communication to better understand their pain language. As one participant continued, “My younger children don’t have the capacity to understand yet. They will in time, and I only hope it teaches them some compassion from the experience of having a mom with pain issues.”

### **2. Pain as fragmented self**

Within this interpretive repertoire is the theme of discontinuity. The way pain interrupted daily functioning and limited potentiality affected participants on social, professional, and psychological levels.

#### **A. Lack of control**

Participants expressed frustration with the lack of control they have over their pain. They talked of “being captured by pain and having it run my life.” Posts attest to the amount of power pain has over them, impacting their body as well as their behavior.

- “The most frustrating part is not being able to control my environment to manage my pain.”
- “I never know when a pain flare-up will happen, and it can happen so suddenly.”

- “I try to shut myself off but it’s not effective. This is when I need drugs to numb me and shut me down. It’s frustrating to have to take them when I know sometimes I can do without them on my own.”
- “I try to see a reason for increased pain, but most often I can’t figure it out. Medical professionals usually don’t know either.”
- “I keep hoping for meds that will come down my immune system only to be disappointed again when my body decides that it will have none of this nonsense and rebels inflicting blisters over my back and head....one more failed attempt to get this diagnosis under control.”

### **Discussion**

These posts illustrate the concept of stake where participants reveal the amount of interest in their pain by using ‘I statements’ that use strong verbs: hope, try, need, know. The sentences they constructed reveal their investment in their pain treatment and the impacts of pain’s lack of control. There is direct responsibility where participants use the active voice and take action. They “try to understand, keep hoping, shut off” whereas medical professionals “usually don’t know.” In this construction, medical professionals are passive. Not only are they not performing any action, they don’t know either. This vocabulary shows the extent of frustration and disappointment individuals with chronic pain have with medical professionals and their perception of “not knowing” minimizes the medical profession’s stake in their health outcomes.

### **B. Discontinuity**

Participants’ posts illustrated the contradiction of how chronic pain is prolonged and persistent, yet it is also variable and unpredictable. The very nature of pain, its ebb and flow, is

fickle. Some descriptions of participants' pain cycles resembled frenzied, almost drug-induced hyperactive periods, followed by idle pain days. The variability conveyed extreme contrasts in their functionality and participants seemed to long for stability. The result of this unpredictability was a fragmented self, where participants' energies, moods, behaviors and functionality were constantly swinging. The volatility created a disjointed self where the chronic pain individual seemed to be split between a pain-free and pain flare-up dichotomy.

- “I am always an on the go person. When I am having pain nothing gets done.”
- “I tend to be an all or nothing person.”
- “On good days I jump out of bed and do everything without difficulty often going into a manic sort of that sometimes leads to another day of pain because I was too active.”
- “It’s like on good days I have to compensate for the poor days so I run around the house cleaning like I’m on speed...I wish I could be more balanced, even keeled. But pain doesn’t let me.”
- “Its [pain’s] volume tends to reflect the waxing and waning intensity of my overall body pain.”
- “I am usually on the go all the time and this is how I like it, so it is difficult to even allow myself the time to take care of the pain.”
- “Sometimes I wonder would it [pain] be better if it was just constant, day after day, so then at least I would know what to expect.”
- “On a bad day, I do less.”
- “With less pain, I talk more. I laugh more. Large pain loads make me disappear.”

- “Pain days for me cause me to ditch my usually over the top plans for accomplishment and focus on my relationship with my family. I want to use my energy I have toward caring for them, and not on the house or the yard.”
- “I may have a productive day at work and have enough energy to tidy the house but then I’ve ignored my boys and husband.”

### **C. Social Anxiety**

The lack of control over their pain, both in its frequency, duration, intensity, and treatment, caused anxiety and frustration. Due to their inability to hold commitments participants were worried about how others perceived and judged them. In turn, their self-esteem was impacted as they felt excluded and ostracized. Participants wrote how their immobility due to pain caused a lack of exercise and subsequent weight gain, thus starting a downward cycle. Other posts demonstrated the extent of social disruption and interference of planned engagements.

- “Can I commit to something when I don’t know how I may be feeling that day?”
- “I worry that I’ll come across as flaky or unreliable when I commit to something and then have to back out because my body has made other plans without my permission.”
- “I have missed a few social events and it makes me down right angry that I am ill and then I tend to eat more to make myself feel better.”
- “Pain, or the expectation of pain, often stops me from trying new things.”
- “I worry I won’t be asked or included in the future if I am deemed too flaky to follow through.”
- “I feel terrible not being fully present in conversations.”
- “Sleep patterns cause me to miss a social event or two.”

- “Pain makes me not want to be active.”
- “Sometimes I’ve already mentally committed to not doing something because I expect pain.”
- “When I do return to health it is so much harder to exercise again and I feel so sluggish.”
- “I am as normal as everyone else and when people find out you have a chronic condition they tend to pass judgment.”

### **Discussion**

The posts invoke Bourdieu’s notion of habitus. As defined by him, habitus is the “structure which organizes practices and the perceptions of practice (Bourdieu, 1984, p.170). It is the system of durable and transferable dispositions that move from situation to situation and is created by socialization with the world through family, education and culture. It allows individuals to react instinctively, intuitively, without making a conscious decision. Bourdieu (1984) links habitus to four different types of species capital, including social capital which can be defined as one’s circle of friends, groups and memberships. One’s social capital is associated with one’s habitus, including skills, education, and social class. Bourdieu (1984) argues that when one’s habitus matches social expectations, everything runs smoothly.

Yet Bourdieu (1984) warns that trouble abounds when one’s habitus doesn’t match social expectations. This is often the case for individuals with chronic pain as pain reshapes their habitus so that past performances may not be any indicator of future performances. Pain is a variable that thwarts expectations, obligations and can weaken social capital. Participants noted that they were fearful to make commitments because they didn’t want to disappoint others if a bad pain day prevented them from fulfilling their obligation. Their hidden pain identity

complicates their habitus because others in their peer group, with similar education or from the same social class, expect them to be able to perform similar responsibilities. Pain changes sufferer's habitus; their actions, thoughts, and beliefs are influenced not only by their social field, but by their pain. Consequently, individuals with chronic pain are left with trying to figure out how to maintain, restore or negotiate their pain identity.

#### **D. Professional disruptions**

Professionally, the unpredictable nature of pain fragmented participants' time, energy and thoughts. Participants admitted they felt their pain compromised their work.

- “I may be in the middle of a project and in the flow of writing and then I'm bedridden and I've lost the narrative.”
- “In pain, I'm unable to type because pain shoots down my arms and wrists. I can't focus. I feel useless.”
- “When continuity is interrupted so often it's difficult to make it through an entire project and feel satisfied with it—kind of leaves me wondering what parts I missed.”

#### **Discussion**

These posts attest to the loss of work productivity noted in the American Academy of Pain Medicine's (2013) report which discussed the connection between chronic pain and decreased ability to function at work. They also reinforce Tveito et al.'s (2010) findings which stated activity interference, negative self-perceptions, interpersonal challenges and inflexibility of work deter pain disclosure at the workplace. Additionally, when individuals with chronic pain miss work due to pain interference, social benefits of working are also lost including social contact, support networks, and a sense of professionalism and self-worth.



### **E. Loss of potential**

Overall, perhaps the greatest loss stemming from the discontinuity of pain was intangible—the loss of potential. Participants wondered what they could do, dream, and accomplish if their health was stable and pain was absent. Some expressed guilt from being less than their best and how that impacted interpersonal relationships.

- “What dreams could I attain? What if?”
- “Pain robs all motivation. I have no hunger, thirst or desire for anything but the pain to stop.”
- “I often feel like a bad friend or bad spouse or bad mother when I am not at my best or when I avoid a social situation because of the pain.”

### **Discussion**

The posts document the detrimental impacts pain exerts not only over participants' bodies, but also in their ability to be a parent, spouse, friend, and employee. The lack of cohesion and the extent of fragmentation on an individual's sense of self may be exacerbated when interacting with a group, whether that be a family or a work group. Poole et al's (2004) research indicates cohesiveness depends on the development of a coherent vision however these posts illustrated the inconsistency inherent with chronic pain. The expressions of unpredictability and guilt reinforce previous studies that have determined chronic pain restricts family life, communications, activities and interactions (Lewandowski et al., 2007) and reinforce how parents with chronic pain face larger obstacles with their parenting tasks (Fagan, 2003).

## **F. Pain as Multi-faceted phenomena**

### **A. Emotional Impacts**

One theme that emerged from the workshop was the interrelatedness of physical pain and emotional impacts. The first writing prompt in the online writing workshop asked participants to take inventory of their pain. In addition to taking stock of their pain, participants were asked to attend to its movement, (where does it start, how does it move across the body,) and notice the direction of the pain (circular, linear, diagonal). Nowhere in the writing prompt did it ask participants to convey any feelings or describe the emotional toll of their pain, but many participants' descriptions of pain were accompanied by their emotional response to pain.

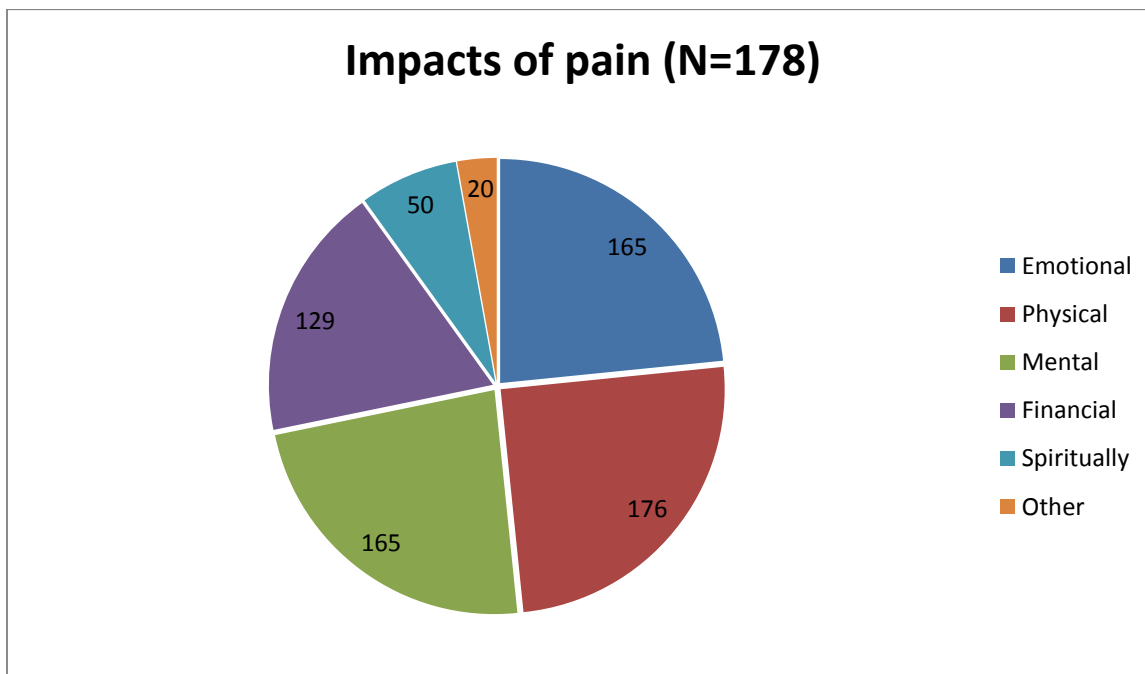
- “When my hands start hurting, I often find myself clenching my fists and staring at my hands; unable to comprehend why now is the time my hands hurt. It begins as frustrating and then anger.”
- “I do not appreciate a pain in my hands that can take away my ability to accomplish simple tasks. I do not understand why it is me that was chosen for this pain.”
- “The frustration of not being able to figure out the ‘why’ can be hurtful in itself. It becomes another barrier to coping with our pain.”

Also, it was noted that emotions escalate pain. One respondent was unable to participate for a few weeks due to a family emergency which heightened her pain and she reported she “was trying to stay out of the emergency room.”

Survey data concur with the inter-related aspects of pain. To determine how survey respondents describe the experience of chronic pain they were asked to select all the dimensions (emotional, physical, mental, financial, and spiritual) which are impacted by their pain. Of the 178 respondents, 99% indicated that pain impacts them physically (N=176). There was a tie for

the second most selected dimension with 93% of respondents selecting emotional and mental (N=165). The fourth highest dimension of impact was financial (72%; N=129), and spiritual trailed by a substantial margin, with only 28% of respondents (N=50) selecting this dimension. Of the seventeen respondents who provided their own textual answer, six (N=6) respondents indicated that their pain impacted them sexually, five (N=5) noted it impacted them socially and two (N=2) said pain impacted everything, “in every aspect of every second of my being.”

These responses testify to the holistic aspects of pain; it cannot be divided up into separate physical, emotional, spiritual, or intellectual realms. They are consistent with Ojala et al.’s (2014) phenomenological approach to explore the effects of chronic pain and the main problem participants complained of was not the physical pain itself but the psychosocial consequences such as distress, loneliness, lost identity and low quality of life. Results are illustrated in Figure 9.



**Figure 9. Impacts of Pain**

The ordering of the impacts of pain from survey respondents does not align with the discourse analysis as mental impacts was one of many themes to emerge, but it was tied for second place by survey respondents. Possible explanations for this discrepancy are that while mental impacts are acknowledged, they are hard to articulate in words. As one writing workshop participant said, “For me...my pain journey is more of a MENTAL battle than a physical one...if that makes any sense.”

The doubt that this participant has regarding if her statement makes sense sheds light on the difficulty in describing the way pain impacts a person. Other participants chimed in with:

- “It’s so difficult to put into words how pain feels.”
- “It is the mental pain that hurts the most.”

Whether conveying emotional or mental impacts, data from both the writing workshop and survey illustrated the inter-related aspects of living with chronic pain and support Larner’s (2013) description that pain is a multidimensional experience, impacting individuals on neurophysiological, biochemical, psychological, ethnocultural, religious, spiritual, cognitive, affective, and environmental levels.

## **B. Comorbidity**

Comorbidity is common among individuals with chronic pain and participants observed the linkage of their physical pain with their emotional state. Approximately a quarter to more than half of the population in the U.S. that complain of pain is also depressed; alternately, 65% of depressed people also complain of pain (Web MD, 2005-2015). This connection between physical pain and emotional and mental health is exacerbated with lack of sleep, side-effects

from medication, daytime fatigue and low productivity. Participants shared how their emotional and mental states are activated by their chronic pain.

- “I also suffer from depression and anxiety and I am certain these health issues are related. I’m not sure which problem causes the other but I do know that my depression worsens in severity during periods of time where I’m experiencing an increase in my pain.”
- “The biggest pain trigger is stress or times of extreme emotion (anger, frustration, sadness, etc.).”
- “Pain has caused my insomnia to be out of control.”
- “I understand people with pain, and how it contributes to making poor choices.”
- “My pain brain is not a nice person. Pain can make me impulsive and crabby and rude.”

### **C. Mental: Pain Decisions**

The notion of pain requiring a high level of decision-making was another key theme to emerge and arose in the context of pain substitutions where one type or location of pain was more tolerable than others and therefore, one type of pain was exchanged for a more bearable other type of pain. Often times, gaining pain relief in one area of the body elicited pain in another. Participants indicated they knew which pain was more bearable than others and made choices to endure one type or location of pain because it was less severe than other types. One participant talked of this type of pain decision-making when talking about pain in her tail bone. After seeking chiropractic treatment for it, new pain emerged. “But now, the new sitting position causes pain in my mid back, it swims back and forth horizontally.”

Additionally, pain decisions resembled an economic risk-to-reward analysis where participants expressed the mental negotiations at play when they were debating whether or not to engage in certain behaviors which may trigger a pain flare-up. One participant wrote about weighing benefits versus consequences when she had to account for pollen counts and wind speeds into her ability to go to her son's baseball game. "My allergies often trigger migraines. But try explaining that to my son. He just wouldn't understand."

Other pain decisions centered on medication and whether increasing the dose was worth the consequence of enduring the side effects. Participants were consciously aware of benefits versus risks when taking their medicine.

- "What really gets me is the second pill. It has to be pretty important for me to warrant a second pill because my pills come with a kind of hangover feeling."
- "When I take a second pill later in the day to get by, and then go do something that isn't worth the cost, I get really mad."

When trying to determine the effect of provoking a known pain trigger participants acknowledged they had to analyze payoffs and pitfalls against the social responses from family. Another participant wrote when discussing if she would confront a pain trigger (chewy foods),

- "If I want one of these things, I have to weigh the consequences of the indulgence each and every time. I ask myself 'Is this Twizzler worth it? It's taxing and takes the joy out of it.'"
- "Yes, sometimes the Twizzler is worth it"
- "There is the physical tax, that constant weighing in on pain. How many days have we lost to pain?"
- "Sometimes, you just want to forget you have pain and fit in."

## **Discussion**

The constant decision-making and weighing of risks and consequences reveals a scripted or routine response to coping with chronic pain. Through the use of scripting participants are normalizing this analytical behavior. In particular, the response which said “the Twizzler is worth it” indicates the extent of pain that individuals may endure to be normal. Through scripting the mental decision-making participants are diverting attention from the physical sensation of pain and focusing on the choices they have.

The ability for these participants to weigh intended consequences against the potential satisfaction is a well-honed skill and could have implications for high order thinking. The amount of analysis that goes into the process of decision-making among individuals with chronic pain may increase their critical thinking as analyzing perceived payoffs and pitfalls is customary. The correlation between chronic pain and increased capacity for decision-making is one area deserving of further research.

### **D. Mental: Aging Impacts**

Participants wrote how living with chronic pain has aged them. They described the longer time period it takes for their body to recover from a pain flare-up and how as they age, their chronic pain is harder to deal with. Some participants claimed that living with constant pain accelerates aging where the physical toll of pain taxes their mind and body. While participants acknowledged the physical toll of pain on their skin, joints, and nerves, there was an underlying mental tax as well that chronic pain imposes on them. As one participant wrote, “that constant weighing in of pain. How many days have we lost to pain?” Additionally, there was a sense of fatigue and feeling of malaise due to pain that slows down their mental functioning.

Similar to how dogs age in multipliers of seven years to humans one, participants shared a similar effect with pain. The advanced signs of aging impact individuals emotionally as well as they perceive themselves as different, as older, than their peers.

- “Pain age, where for every year you need to multiple your age by 7.”
- “I feel I’m a youngish woman trapped inside a 65 year old body. I’ve aged so much compared to my friends. I feel like pain has tacked on 20 years.”
- “I’ve noticed as I age my body takes longer to recover. I feel pain more acutely and it lingers longer.”
- “It takes a little longer to get out of bed. Playing with my grandchildren is not as active as I would like it to be.”
- “I’m only 44 and feel like I’m 80 sometimes.”

## **Discussion**

These reports of accelerating aging due to pain are consistent with research that shows individuals living with chronic back pain, fibromyalgia, irritable bowel syndrome and headaches may reduce the volume of brain tissue as much as 11 percent (Apkarian et al., 2004). According to the researchers, the magnitude of this decrease is equivalent to the gray matter volume lost in 10 –20 years of normal aging and it was related to pain duration, indicating a 1.3 cm<sup>3</sup> loss of gray matter for every year of chronic pain (Apkarian et al., 2004).

It is important to point out that the participants’ responses triggered the need to corroborate their accounts with research. In this way, the personal accounts triggered research and show the validity of subjective and constructed knowledge. The first-person narratives complement the scientific findings by showing the emotional effect of the advanced aging brought on by chronic pain. They give testament to Thorgaard’s (2010) argument for using



approaches that rely on first person accounts as readers can understand the effect of accelerated aging in poignant ways. To validate participants' perception, uphold Belenky's et al. (1986) claim knowledge gained through life experiences and first hand observations are valued, and alleviate any feelings that participants may have regarding the idea of pain years as "all in their head" providers may want to forewarn chronic pain patients of the advanced aging effects. Informed patients can be aware of having to adapt their physical activities and their expectations for aging.

### **E. Spiritual Impacts**

Participants wrote how the experience of pain had increased their spiritual life. Some participants linked the invisible nature of pain with the invisible nature of faith as both concepts are unseen and immeasurable. Many participants mentioned that they "pray", have "faith in God" and that their "spirituality gave much needed strength." Others expressed how their pain has made them turn to or rely on their faith even more. Sentiments like these highlight the connection between pain and faith. The idea that the invisible nature of pain increased their faith in the unseen spiritual world is an idea worthy of future exploration. As participants wrote:

- "Listening to my body speak has helped me tune in to hearing God's voice. Pain and prayer are close friends. No one knows I'm praying, no one knows I'm in pain. Pain has strengthened my prayer life."
- "I can train my thoughts on health and strength when I'm in the grips of pain. I can go inward and shut down. This takes a lot of mental power but retreating inward really helps."
- "Pain has given me a greater thirst for Heaven."
- "The only thing that gets me through the night is prayer."

- “These silent forces have had such an impact on my life. Pain has strengthened my prayer life.”
- “My faith continues to be a big part of my life.”

These statements highlight the impact that unseen forces have on participants’ lives and warrant future studies exploring the connections between pain, religion and spirituality.

## **F. Pain as teacher**

The final repertoire to emerge from the online writing workshop characterizes pain as a teaching tool. Participants wrote in great detail how having chronic pain has taught them life lessons. Four ways in which pain has served as a teacher is by instilling the value of respect, cultivating compassion, promoting self-care and fostering a sense of permission-giving. While most of these themes emerged in the last writing workshop assignment in which participants had to write a thank you letter to their pain, participants expressed the value in having chronic pain throughout the workshop.

### **A. Teacher: Respect**

Participants shared that while pain is something they want to eradicate from their life, pain also must be respected. Pain has shaped them as individuals, strengthened their character and made them more aware of their time when they are pain-free. In terms of lessons learned from pain participants shared how they have learned honesty about their limitations. They have trained themselves to not apologize for their pain or its impacts. Participants expressed that pain has made them more thankful for what they can do and appreciate their family. Time took on an elevated role as participants became aware of the limited time they have being pain-free and how they needed to be selective about how they spent their time.

- “I must respect myself and act in my own best interests.”

- “While it is difficult to fully understand unless you’ve been through it yourself, it should not prevent you from showing respect to a person’s need to cancel plans to take care of a pain flare-up.”
- “I have learned to have sharper edges. I don’t have time or energy to skirt the issues.”
- I’m also learning not to apologize when the reason for backing out of my commitment is because of pain’s excessive demands and not because I’m lazy or unconcerned about others.”
- “I’m learning to be more decisive.”
- “I’ve learned to cut the crap. We don’t have time to brush the tough things under the rug.”
- I have learned how important it is for me to value my time and to use it constructively.”
- “Pain demands respect and attention and if it is ignored the price can be high.”
- “There’s a lot of value to our experience of living with pain. Unfortunately, what we learned is often not valued by the world we live in. We can learn not to judge or criticize the actions of others too quickly—there’s more to the story. There’s lots to be learned—it’s all good—just not all fun.”
- “It MUST be respected for US to be in charge and not the pain.”

### **B. Teacher: Compassion**

Participants discussed how the experience of living with chronic pain has instilled in them a stronger sense of consideration for others. Specifically, participants wrote they have learned to be more compassionate to others, even when they can’t relate.

- “I have more patience toward people who move slowly”

- “I am aware of the efforts that people put forth to get through their day because of their pain.”
- “The push I give myself through these physical activities makes me see how tough it is for those with physical disabilities.”
- “I am much more compassionate toward senior citizens. In the past I was frustrated that they moved slow walking in stores, drove slow, etc. But I often think to myself about my own issues and can actually put myself in their shoes.”
- “When I’m frustrated with somebody who doesn’t move fast enough to please me, I remind myself—‘that’s me.’”
- I have learned to acknowledge and understand someone’s concerns even if I don’t share the same ones as they do.”

They also showed a global awareness and concern for others who are “suffering all over the world” that have never had the privilege of being seen by a doctor and know nothing other than a life full of pain.” Other participants said pain has taught them compassion “for people who live with it way more than I do and are never without pain.”

Posts like these shed light on a pain lens with which individuals with chronic pain view the world. It highlights the way that chronic pain filters everyday life. As residents of a developed world, participants are aware of their privilege and access to modern medicine. While they are grateful for the accessibility, there is an underlying emotion of empathy if not humility. “I think of mothers who have nothing and have to watch their children endure pain. I think of people who have no access to medicine or doctors and I feel so grateful.”

In this way pain has served as a bridge to connect with disparate others around the world. Due to the commonality of experiencing a life full of pain, sufferers were uniting across borders

and time. This ability to connect with similarly affected individuals across geographic locales brings to mind what Castells (2002) talks about when discussing the networking ability of Internet technology and highlights the potential of online support groups. If individuals with chronic pain are already aware of and thinking of similar others, than connecting them through Internet technology seems a logical next step.

### **C. Teacher: Self-Care**

The theme of taking care of oneself was overshadowed by a sense of struggle. Participants seemed to be at odds with their simultaneous roles as wives and mothers where taking care of others comes first, and themselves as patients. The idea of putting themselves first and tending to themselves was counter-intuitive and something they have had to learn. Others acknowledged a sense of guilt they have for taking time to care for themselves, for having to back out of commitments, or for not being at their optimal level. Learning to ask for and accept help seemed to be a monumental accomplishment for some participants.

- “I’ve learned to ask for help without feeling ashamed (most of the time).”
- “Don’t blame yourself and take care of you.”
- “The biggest gift pain has given me is to MAKE ME CARE FOR MYSELF. I would never do that if I didn’t HAVE to.”
- “I do take care of myself, respecting my pain when it tells me I need a nap or I need to soak my feet.”
- “We are taught to be so self-sufficient and think of others first. It’s really hard to put myself first, my own needs, especially as a woman. Motherhood and wifhood come first.”

- “As I take care of myself, I need to offer the same respect to others. My circumstances afford me opportunities to learn compassion and wisdom.”
- “I have become more self-aware and learned to slow down and enjoy down time.”
- “I have learned to listen to my body, to give into it instead of fight it.”

Additionally, these posts reveal a cultural code known as Janteloven that is popular among Scandinavians where thinking of and care for the group is prioritized over thinking of and care for self (Sandemose, 1936). This cultural norm is illustrated by the participant who after discussing that she has chronic pain, fibromyalgia, asthma, acid reflux, chronic sinusitis, hypothyroidism, depression and anxiety issues, she writes, “Through all this I still smile and remind myself that I have a very caring and loving family. Hopefully my positive attitude is infectious and touches at least one other person doing this workshop.” Her selflessness, ability to focus on the positive, and priority of putting others first is concurrent with the Janteloven custom.

#### **D. Teacher: Permission Giving**

The ability to grant permission to oneself to take it easy and to listen to one’s body and its needs was another area of struggle for participants. The notion of granting permission often came in the form of advice where participants were counseling other sufferers on coping mechanisms.

- “I have also learned to be kind to myself. I do the necessary jobs around the house, sit and rest, and begin again---and sit and rest again!”
- “Give yourself permission to grieve over the loss of normality.”
- “Don’t hesitate to give yourself permission to crash...it happens.”
- “I must not apologize for who I am, for my abilities or for honoring my choices to take care of myself.”

- “Honor my pain. Honor my attempts at living with it. Don’t give me any advice.”
- “I give myself permission to be ‘off.’”
- “Part of my pain plan is also to be forgiving of myself: to understand and accept that the pile of papers isn’t hurting anyone.”
- “Be a bit stingy with your good days and use them to the fullest.”
- “How many good days have I blown in the office or doing laundry or dusting instead of flying kites or dancing? I will be on guard!”
- “I have learned to ignore what others may want for me and do what I think is best for me.”
- “I give myself permission to hurt and rest and say NO. I give myself permission to go to bed early, or to nap if I need to.”

### **Discussion**

The responses that fall into the interpretive repertoire of pain as teacher reveal a new lens with which individuals with chronic pain view the world. Rather than perceiving themselves as victims, these posts illustrate the extent of stake they have in their chronic pain experience (Silverman, 2011). Their ability to regard pain as a teacher shows how they have accepted their chronic pain. They are not trying to eradicate it or cure it, but have accepted it as what it is and are using it as a teaching tool. Rather than say what they do or don’t do, (“I don’t apologize”) they phrase it as what they ought to do “I must not apologize...” This construction takes on the form of a reminder where they are reinforcing their credo.

Moreover, these posts illustrate the extent of authority the participants have gained from their chronic pain persona. Their words of wisdom and advice are said with confidence, composed using strong commands “Honor my pain.” There is a boldness and sureness in their

instructions where they hold power. They are not asking for approval or requesting permission, but rather they are the ones in charge, granting requests “I give myself permission...” Their sense of ownership with their chronic pain reveals how they make sense of their experience.

These interrelated repertoires offer meaningful insight into participants’ experiences and their collective understanding of what it is like to live with a concealed disability. The benefit of this analysis is that it shows multiple ways in which the experience of chronic pain impacts individuals and how the sufferers change their language and present different personas depending on the context. The reliance of narrative extracts from participants and an examination of their naturally occurring talk in a casual yet anonymous setting positions this study as a unique contribution to the chronic pain literature. Although the interpretive repertoires of ‘pain as discredited self’ and ‘pain as fragmented self’ are well documented themes in the chronic pain literature, ‘pain as teacher’ offers a new angle which bestows confidence and authority to individuals with chronic pain.

## **II: Quantitative Results**

### **Survey Results: Respondent Characteristics**

Respondents who took the survey are representative of a broader chronic pain population in terms of gender. Specifically, the fact that there was three and a half times the amount of female respondents than male respondents is consistent with gender trends inherent within the chronic pain population as females are at a significantly greater risk of developing a pain condition and disproportionately suffer from chronic pain (Elliot et al., 1999; Edwards, 2013). The Institute of Medicine (2011) estimates about 116 million Americans suffer from chronic pain and a report produced by the Chronic Pain Research Alliance states 50 million American chronic pain sufferers are women (Ballweg et al., 2010). However, this is not to suggest that men



do not experience or disclose their chronic pain. Twenty-two percent of the survey respondents were male which shows men are actively using online chronic pain forums and social media as support outlets.

The survey sample was decisively younger than anticipated. Demographic trends among chronic pain sufferers show a higher prevalence rate of senior citizens, with those aged sixty-five and older reporting longer duration of pain (Wertich, 2014) yet the largest age bracket within the survey sample was those aged between 25-34 years (33%). In fact, nearly three-fourths of the survey sample (73%) was under 44 years of age. This young population diverges from a representative chronic pain sample, but is characteristic of social media users. In particular to Facebook, on which the survey was posted on chronic pain devoted sites, data compiled from the Pew Research Center on social networking platforms (2014) shows that users aged 18-29 have the highest usage of Facebook (87%), followed by 30-49 years olds (73%). In terms of Facebook usage, the Pew Research Center (2014) identified that 70% of users say they use Facebook daily and most Facebook users actively engage with their networks, with 65% posting or commenting. Additionally, women are more likely to use Facebook compared to men (77% vs. 66%). It is from within this actively engaged Facebook user that many respondents took and/or shared my survey.

Other survey characteristics consistent with online trends are race and level of education. The majority of survey respondents (90%) indicated they are white; similarly, whites represent the highest incidence rate among adults who use the Internet (85%) (Pew Research Center Internet Project Survey, 2014). Additionally, the survey sample was highly educated with 81% of respondents completing some college or higher. Twenty percent of the survey sample had a masters, doctorate or professional degree. This educated sample is consistent with Internet usage

trends as 97% of Americans who use the Internet have a college degree or higher (Pew Research Center Internet Project Survey, 2014).

Further, the breakdown of the survey respondents' gender with 78% identifying as female is consistent with gender representation on the internet. American women are particularly active online, with one in three bloggers being females. This disproportionate presence of female bloggers may be linked to the fact that women are more likely than men to assume responsibility for both their own and their families' health needs (Misra, 2001).

These survey demographics highlight the important considerations for methodological choice. The selection of using computer mediated communication for both the qualitative and quantitative methods targets an Internet-savvy population within the chronic pain population. This niche market is younger, educated and consists predominantly of white women. While these demographics diverge from the average chronic pain sample, it presents a snapshot of who chooses to use Internet technology as an outlet for education, support and/or therapy for their chronic pain condition. This younger and educated population may provide unique insights about the ways they are interacting with anonymous others and navigating a network of users to create what Castells (2002) refers to as cultural communes. Within social media sites, disparate users break the constraints of geographical distance, time and mobility and create the foundation of collaboration (Miller, 2011).

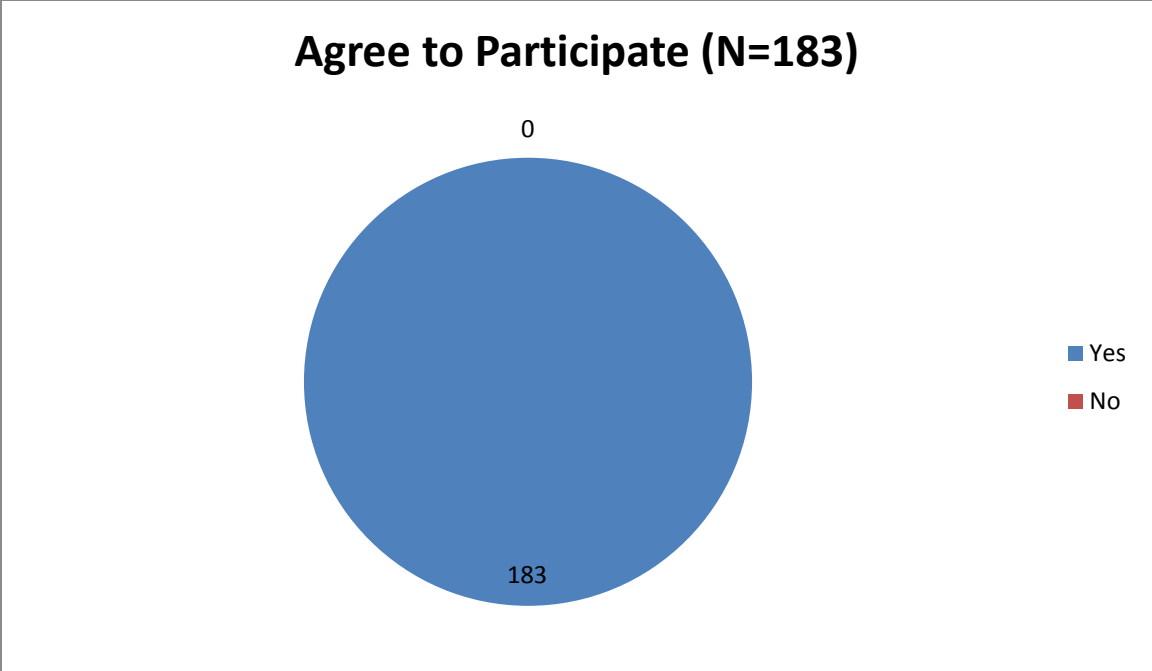
### **Survey Engagement Trends**

Within the two week time period of February 25 to March 13, 2015 in which the online survey was available, 197 respondents started the survey and 157 completed it, equating to an 82% completion rate. A meta-analysis of respondent statistics show that as the survey progressed, respondents' completion rate fell, with a 5% dropout rate after question 14. This

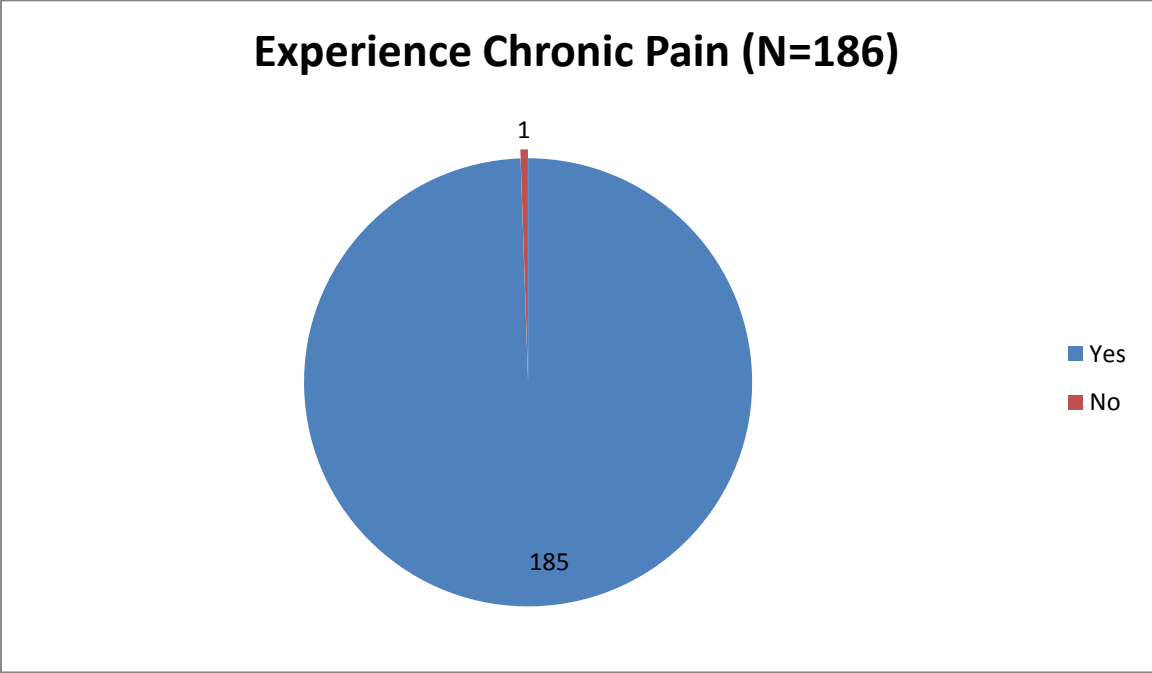
could imply the survey was too long. Respondents were least likely to respond to the geographic question, with only 77% of respondents providing their location. Smaller completion rates could be explained by the fact that for this question, unlike the other demographic questions which were multiple choice, respondents had to type in their locale.

The most popular time for respondents to take the survey was 11am, with 10% of respondents taking it at that time, and Sunday, March 15, 2015 was the day that received the most traffic, with 35% of respondents completing the survey on that date. On average, (56%) respondents took between five to eight minutes to complete the survey. These patterns may shed light on how best to target individuals with chronic pain in the future.

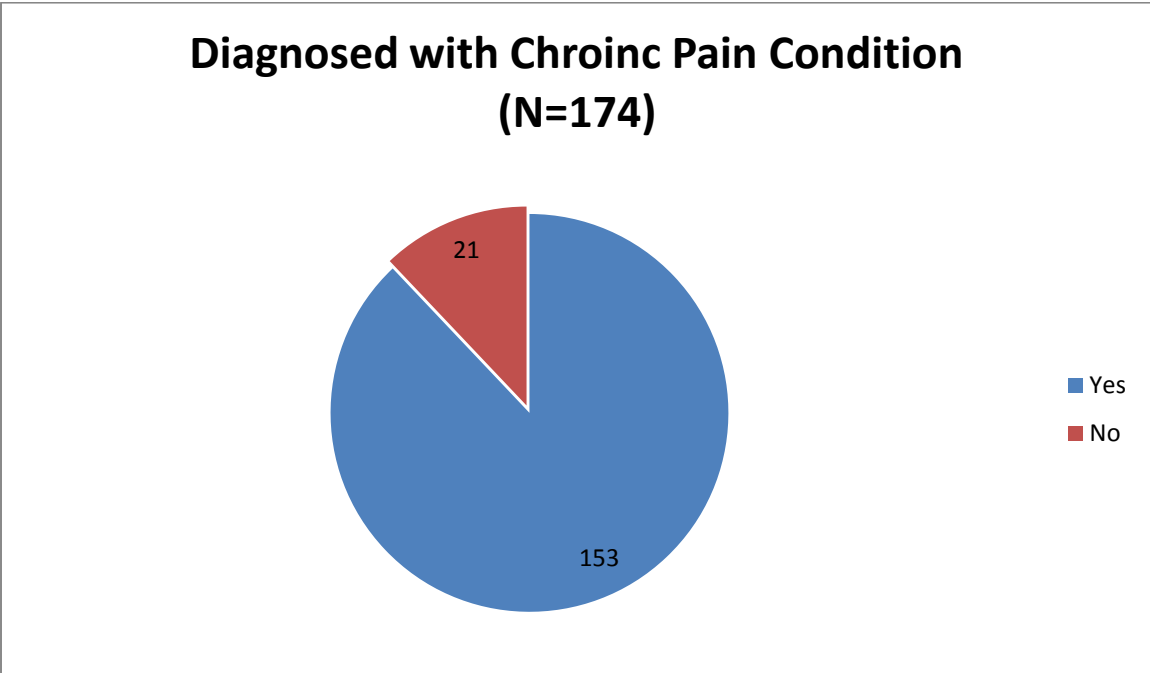
All respondents (100%) read the informed consent procedures and agreed to participate in the survey. Almost all respondents (99%) who took the survey experienced chronic pain, and the majority (88%) had been diagnosed with a chronic pain condition. These results show that this survey was targeting the intended audience of individuals with chronic pain. Figures 10-12 show respondent characteristics.



**Figure 10. Number of Respondents who Agree to Participate**



**Figure 11. Number of Respondents who Experience Chronic Pain**

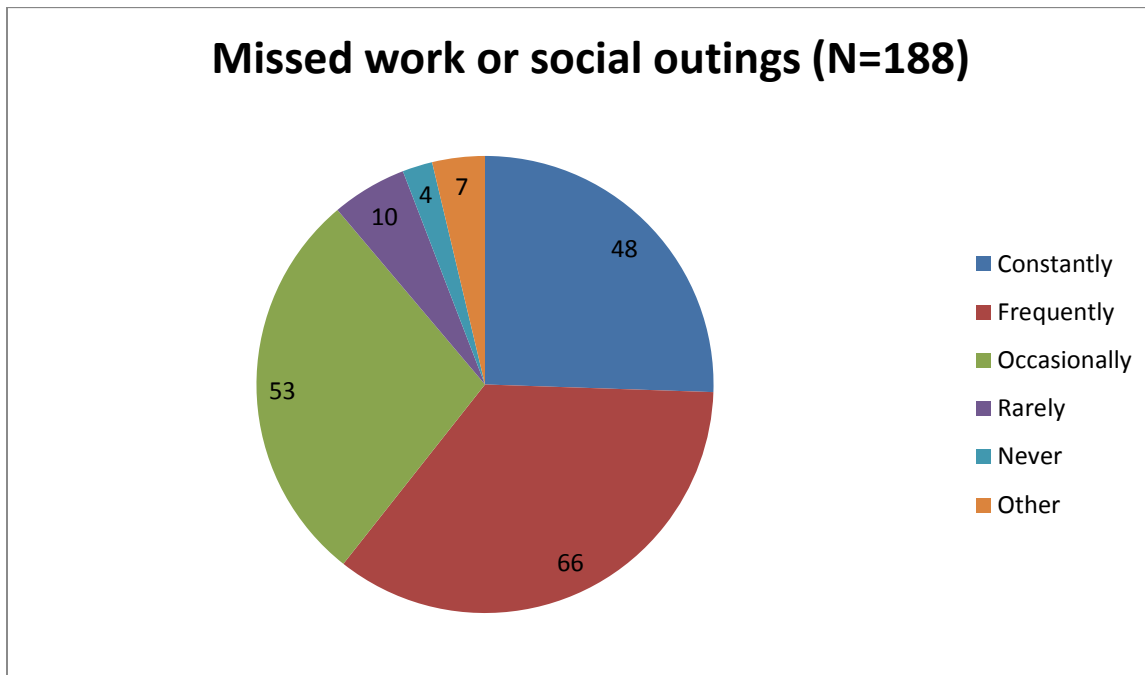


**Figure 12. Number of Respondents Diagnosed with Chronic Pain**

**Impacts of Pain**

To try to gauge the extent that chronic pain had on professional responsibilities and social commitments a survey question inquired if respondents had to miss work or cancel a social outing due to their pain. The vast majority of respondents indicated they often had to miss work or cancel a social outing due to chronic pain. Of the 188 respondents answering this question the highest response category was “frequently” (37%; N=66); the next highest response category was “occasionally”, (30%; N=53); followed by “constantly” (27%; N=48). Only eight percent of respondents indicated that that they “rarely” (6%; N=10) or “never” (2%; N=4) had to miss work or cancel a social outing due to pain. Seven respondents described the impacts of pain in their own words including one who said, “I no longer work and my dreams, goals and the person I

thought I was going to be will never happen.” Four others commented that they could no longer work. Results are shown in Figure 13.



**Figure 13. Number of Respondents Who Missed Work or Social Outings**

These findings which convey chronic pain frequently impacts work responsibilities are congruent with findings from the Voices of Chronic Pain Survey (2006) which reported workers lost an average of 4.6 hours per week of productivity due to a pain condition. Additionally, the congruence that this the sample population, which consists of self-identified individuals with chronic pain, has with the existing chronic pain literature lends validity to the findings.

### **Research Questions**

RQ 1: How does communicating with medical providers influence communication preferences among individuals with chronic pain?

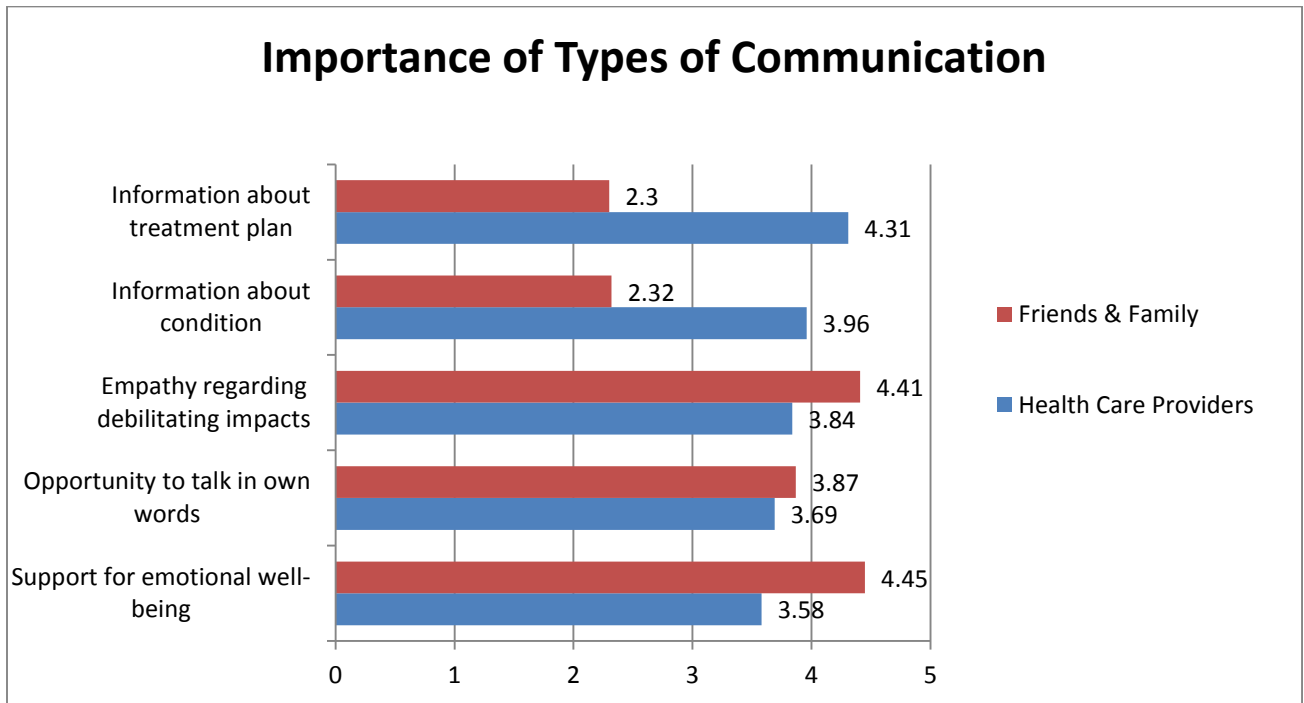
RQ 2: How does communicating with non-medical providers influence communication preferences among individuals with chronic pain?

These two questions will be discussed simultaneously; while the data differentiate communication preferences between the two audiences, the overall discussion is placed on the determinate of audience and context in which the communication occurs. To answer these research questions, data from both the writing workshop and the survey will be synthesized and consulted. In this way, the qualitative anecdotal evidence is placed alongside the quantitative data to provide a "reasonably viable portrait" of findings and is consistent with convergent analysis techniques and multi-method approaches (Nguyen, Attkisson, & Bottino, 1983, p. 104)

The data indicated that the type of communication respondents would like to receive is greatly dependent upon audience. Survey results reveal that when individuals with chronic pain talk with their health care provider, respondents prefer to be offered information over validation and emotional support. Respondents overwhelmingly ranked information about their treatment plan as their number one priority. On a five point scale, receiving information about their treatment plan had a mean of 4.31. The second most sought after information from health care providers was information about their chronic pain condition (3.96), followed closely by empathy regarding the debilitating impacts of chronic pain (3.84). The opportunity to talk about pain using their own words ranked fourth (3.69) and the least important item they would like to receive from their health care provider was support for their emotional well-being (3.58).

The data indicate that when individuals with chronic pain communicate with people that are not medical professionals communication preferences change substantially. When respondents ranked the types of communication offerings that they would like to receive from family and friends, the highest-ranked item was receiving support for their emotional well-being, with a mean score of 4.45, on a five point scale. The second most important communication offering from family and friends was empathy (4.41). In third place was the opportunity to talk

about pain in their own words (3.87) and soliciting information received the lowest rankings, with information about their treatment plan (2.30) trailing information about their condition (2.32). These findings are displayed below in Figure 14.



**Figure 14. Importance of Types of Communication**

### **Preferred Prompts from Health Care Providers**

An additional survey question inquiring about communication preferences reinforces the determinate of audience. The exact wording of the question was “To better understand my chronic pain, I wish my health care provider would ask me more about how chronic pain...”. Respondents had seven response options to choose from, including daily activities, social and family relationships, work responsibilities, self-esteem, goals and dreams, nothing, and other;



respondents could choose all responses that applied. This same question was repeated to target family and friends.

Three quarters (77%; N=125) of all respondents indicated they would like their health care provider to ask them about how pain impacts their daily activities. There was not a great distinction between the rankings of the other options targeting health care providers, with only five percentage points differing between responses. Two-thirds of respondents (68%; N=110) selected inquiring about how pain impacts their social and family relationships, followed by work responsibilities (63%; N=102), goals and dreams (61%; N=99), and self-image and self-esteem (57%; N=93). Only two percent of respondents (N=4) selected they didn't want to talk to their health care provider about any of these.

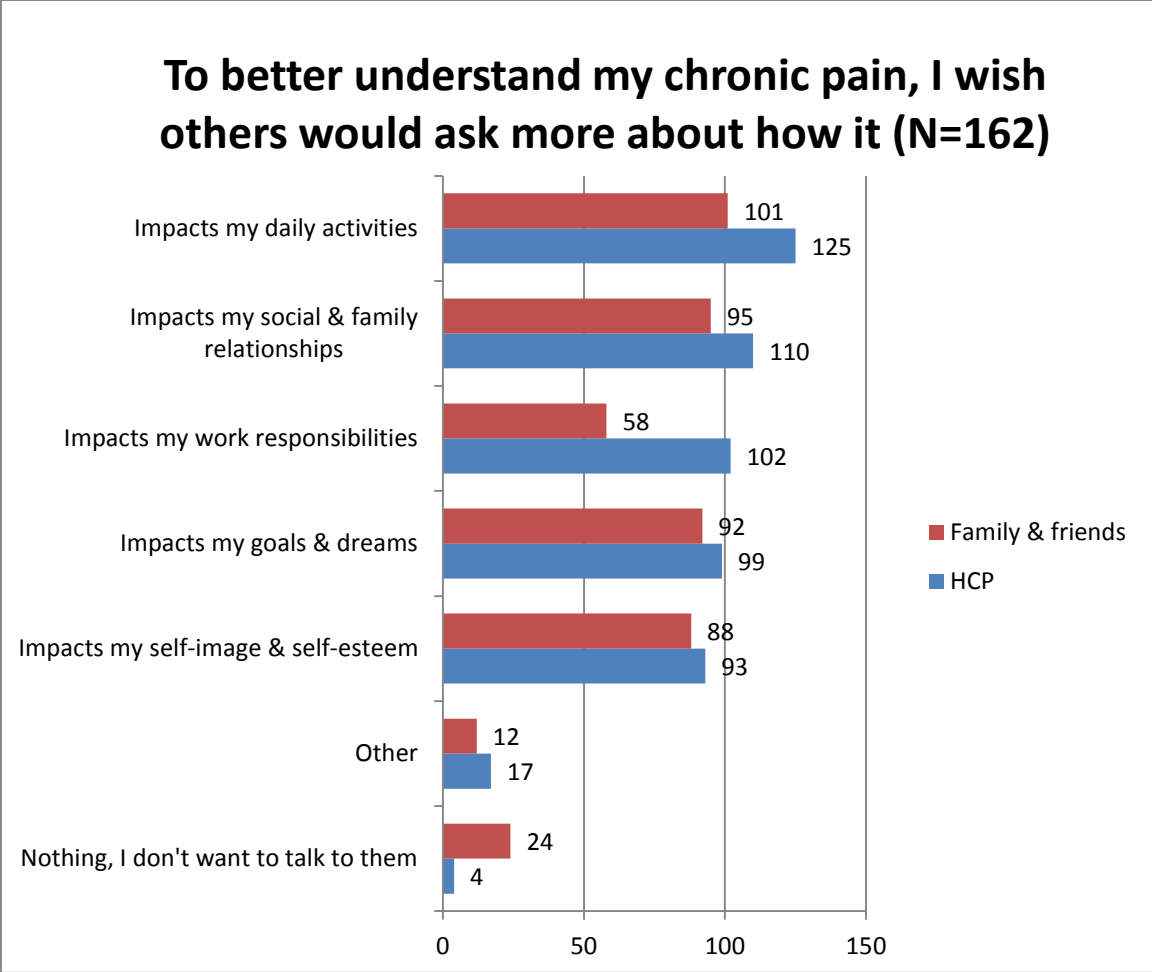
The ordering of these results mirror Maslow's (1943) hierarchy of needs where physiological needs like daily activities are first order needs, work and social relationships represent second order safety and security needs, and the higher level needs for self-esteem and self-actualization are represented by the lower ranked questions pertaining to goals and dreams along with self-esteem. This ordering suggests that individuals with chronic pain want to ensure their health care provider understands their basic needs are met before moving onto higher order functioning.

Of the seventeen (10%) textual answers provided by respondents five confirmed their doctors ask and discuss these things with them while two indicated their doctor does not ask. Other areas of impact respondents would like to be asked about by their provider so that they better understand their chronic pain are depression, sleep and other aspects of their health and ability to enjoy retirement.

### **Preferred Prompts from Family and Friends**

When the audience shifted to family and friends trying to understand the impacts of their chronic pain, respondents similarly prioritized questions pertaining to daily activities (62%; N=101) and social and family relationships (59%; N=95) as their top two, but the ordering of the other prompts changed. The third most selected prompt respondents wanted family and friends to inquire about was their goals and dreams (57%; N=92), followed closely by self-image and self-esteem (54%; N=88). Trailing the list by a large gap were questions pertaining to work responsibilities (36%; N=58). Fifteen percent of respondents (N=24) indicated they did not want to talk about their pain with family and friends, which is substantially larger than the 2% that did not want to talk with their health care provider.

Textual responses suggest that when respondents talk about their pain with family and friends, they do so to enlist help. Five of the 12 written responses explicitly state some form of the response: “just want their help.” Complete results for both health care professionals and family and friends are shown in Figure 15.



**Figure 15. Preferred Prompts to Better Understand Pain**

The data indicate that audience plays a large role in determining communication preferences for individuals with chronic pain and highlights the way individuals with chronic pain turn to family and friends to provide them with emotional support. The data suggest that family and friends can potentially fill a need individuals with chronic pain have by offering them emotional support, empathy, and allowing them the opportunity to speak in their own words.

**Communicating Emotional Support**

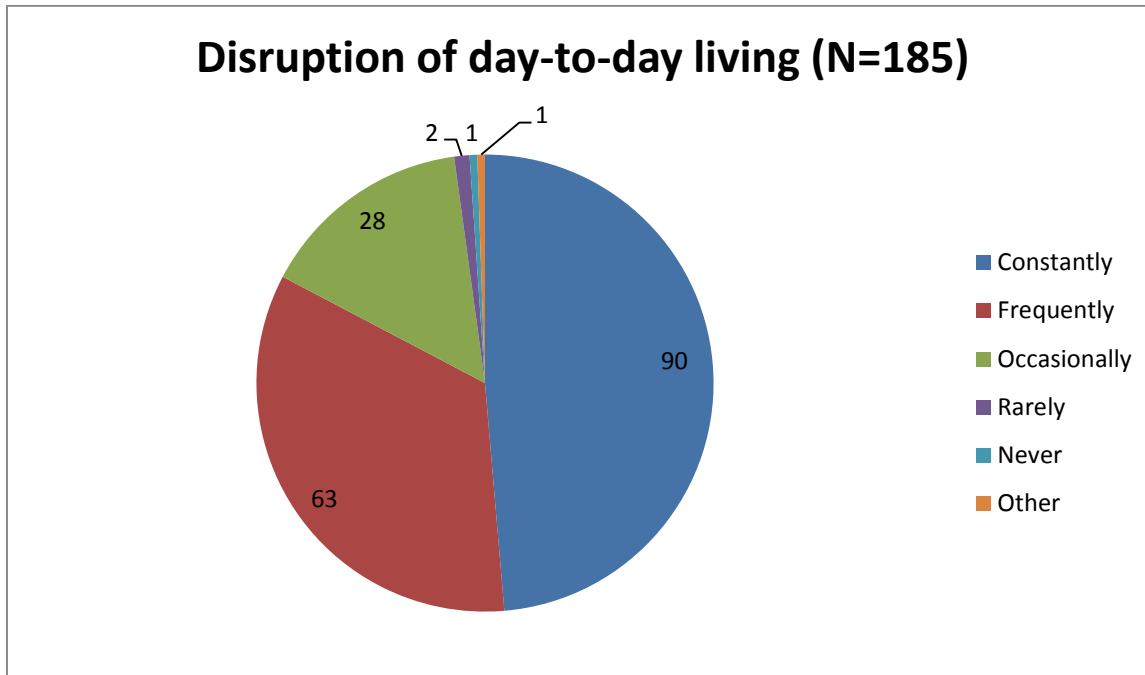
To cultivate an atmosphere of emotional support, family and friends need to take interest in an individuals’ chronic pain condition. One way to demonstrate this interest is for family and friends to inquire about the way pain impacts a sufferer as the majority of respondents indicated

they feel emotionally supported when they talk about their pain with family and friends. Data indicates that allowing them to talk about their pain, in their own words, will not only support them but allow them to reflect on some of their higher order needs. As specified in their closely ranked second, third and fourth ranked selections, respondents would like family and friends to ask them about the way pain has impacted their social and family relationships, goals and dreams as well as their self-image and self-esteem. Asking open-ended questions pertaining to these areas can shift the conversation of pain, focusing not on physical descriptions but on deeper, personal areas of impact. By discussing these personal visions, the sufferer is able to reflect on the process of living with pain, instead of the product, the pain itself. This cause for introspection and reflection may help individuals with pain disclose their needs and foster a better understanding of how to care for their loved one.

Additionally, a large majority of the writing workshop posts conveying the ways in which chronic pain impacted their life was in domestic areas of household cleaning. This impact was discussed in the ‘discredited self’ repertoire where visible effects of pain took on the tangible form of household clutter. The communication prompts that may work best to foster pain disclosures are not ones which focus on pain levels or symptoms. Rather than inquire about bodily sensations, family and friends would be wise to inquire about daily functioning that may be hampered due to pain and relationships that may be impacted.

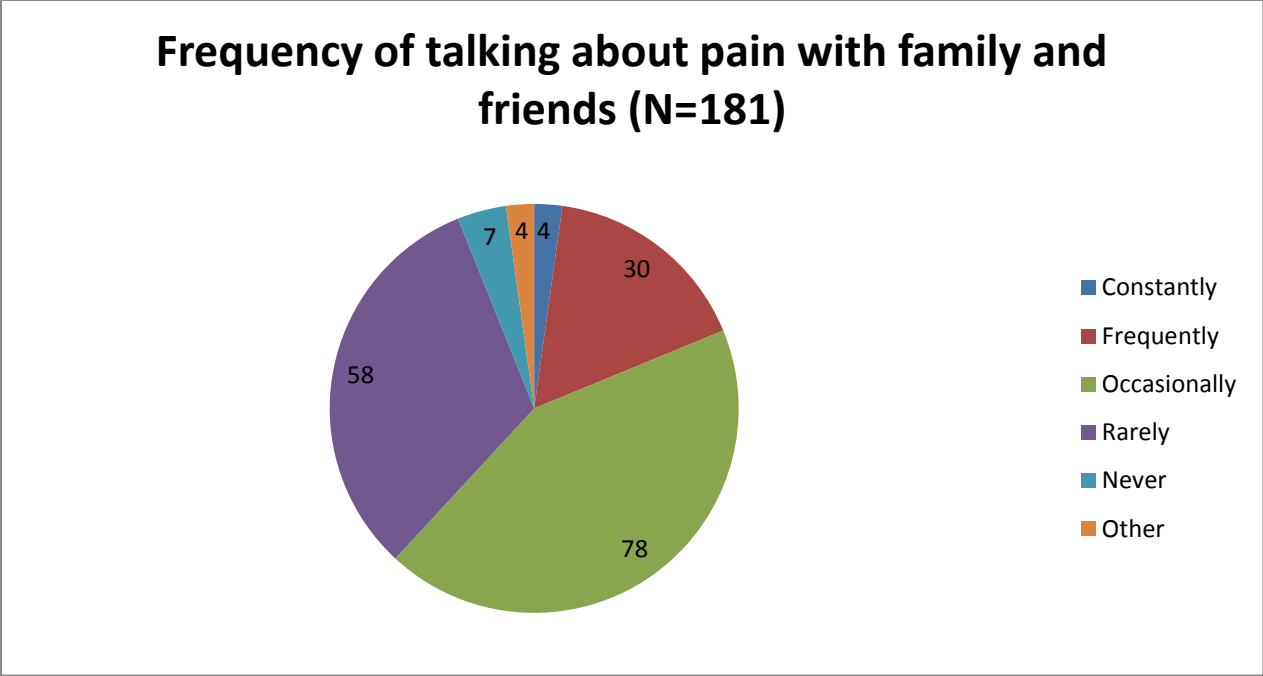
This recommendation is also supported by the fact that a majority of respondents, (51%; N=90) indicated their pain “constantly” disrupts their day-to-day living. One-third (35%; N=63) of the 185 respondents to answer this question said their pain “frequently” disrupts daily functioning. Only one percent (N=1) of all respondents indicated their pain “rarely” or “never” disrupts their daily living. These findings give testament to the extensive impact chronic pain has

on a person’s daily functioning and shed light on the importance of family and friends to change the focus of their inquiry from physical and bodily questions to a broader framework of their social, emotional and environmental health. Results are illustrated in Figure 16.



**Figure 16. Disruption of Day-to-Day Living**

Even though a majority of respondents stated pain “constantly” disrupted their daily functioning, only 2% of respondents (N=4) reported they “constantly” talk about pain to family and friends. Survey data show only a modest amount of pain communication ensues in everyday conversation. One-third (33%; N=58) of respondents reported they “rarely” talk about their pain to friends and family in everyday conversations and less than half (44%; N=78) of respondents indicated they talk “occasionally”. Twice as many respondents reported they “never” talk about pain (4%, N=7). This finding accentuates the importance of family and friends asking these broader contextual questions as pain communication and disclosure are not self-coming. Asking open-ended questions can engender better understanding of the impacts of their pain and facilitate emotional disclosure. Results are shown in Figure 17.

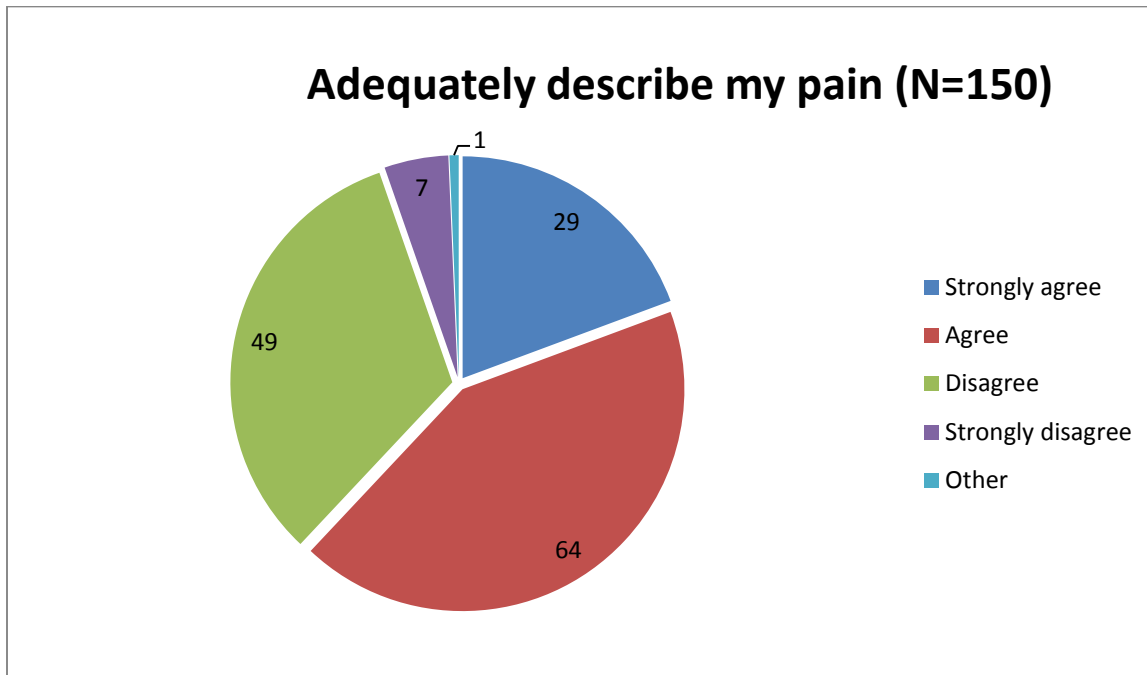


**Figure 17. Frequency of Talking about Pain with Family and Friends**

To try to determine if the reluctance to talk about pain was due to a lack of language sufficiency, a follow-up survey question asked respondents if they felt they could adequately describe their pain. Overall, the majority (62%; N=93) of the 150 respondents indicated some form of agreement with the statement that they could adequately describe their pain. Almost a fifth of all respondents (19%; N=29) specified that they “strongly agreed” with the statement that they could adequately describe their pain while only a minority (5%; N=7) “strongly disagreed” with the statement.

While linguistic competency has been identified as a barrier to effective communication between providers and patients, especially for patients with limited English proficiency (Think Cultural Health, 2011-15), these results indicate language competency is not an obstacle to pain communication among this sample. Communication problems between provider and patients may still exist for respondents in this sample as many studies have acknowledged the critical role communication plays and the myriad constraints to achieving effective communication (Beck,

Daughtridge, & Sloane, 2002; Hall, Roter, & Rand, 1981; Maguire & Pitceathly, 2002; Tongue, Epps, & Forese, 2005; Wright et al., 2003), however, this survey data suggest that communication problems do not arise from patients' inability to articulate their pain. Results are shown in Figure 18.



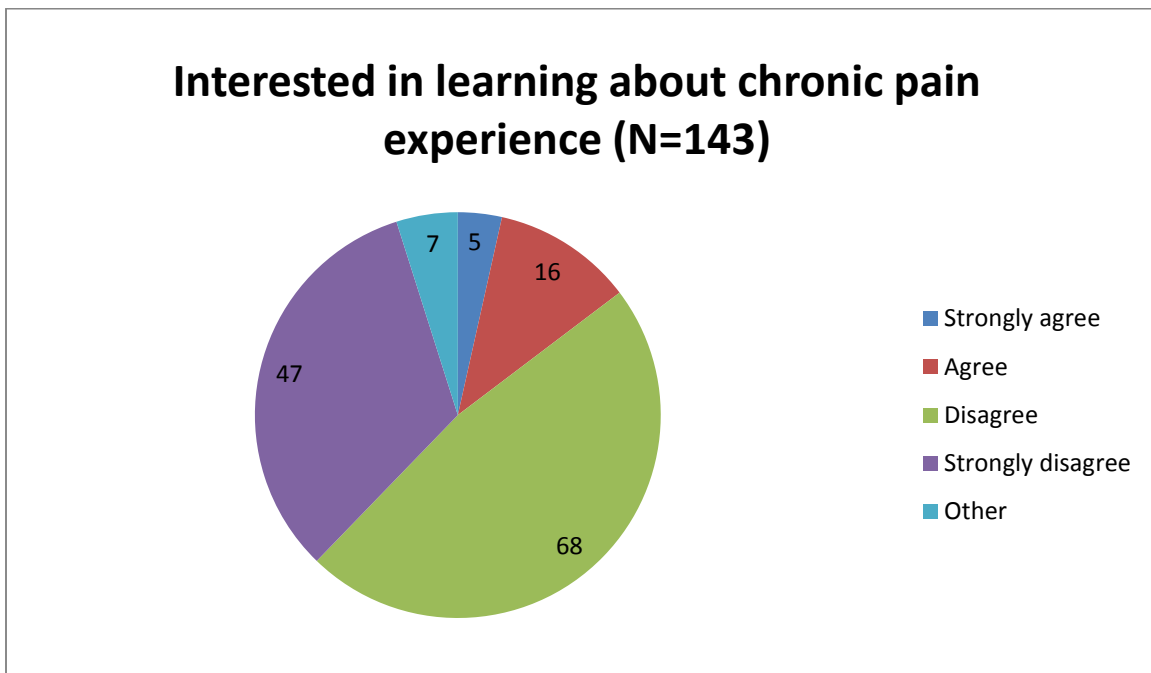
**Figure 18. Ability to Adequately Describe Pain**

With the majority of respondents indicating they can adequately describe their pain, these findings indicate that the reluctance to talk about pain does not arise out of a structural linguistic issue. Survey data suggest respondents' reticence may come from a perceived lack of interest from others. Overall, respondents did not feel others were interested in learning about their chronic pain experience. A resounding 83% (N=115) of the 143 respondents indicated some form of disagreement with the question "I feel others are interested in learning about my chronic pain experience." Nearly half of the respondents disagreed with the statement (49%; N=68) with a third (34%; N=47) strongly disagreeing. Only 4% (N=5) strongly agreed with the statement

that others were interested in learning about their chronic pain experience, as shown in Figure 19.

Seven respondents provided thoughtful explanations including:

- “My experience is dismissed because I'm ‘too young’ for it.”
- “It simply seems necessary to inform others, as it changes day to day. This often leads to cancelled plans and other issues.”
- “Who wants to hear it?”
- “Have lost friends over the years due to their assumptions about "drugs" I'm taking.”
- “In my experience, it's only to ask questions like "How does your boyfriend manage to have sex with you if it's sore to touch you?" How rude.”
- “After 15 years everyone including myself tires of it. People want to feel understood, but it’s not really possible with pain. I try and not talk about my pain unless I really need to.”



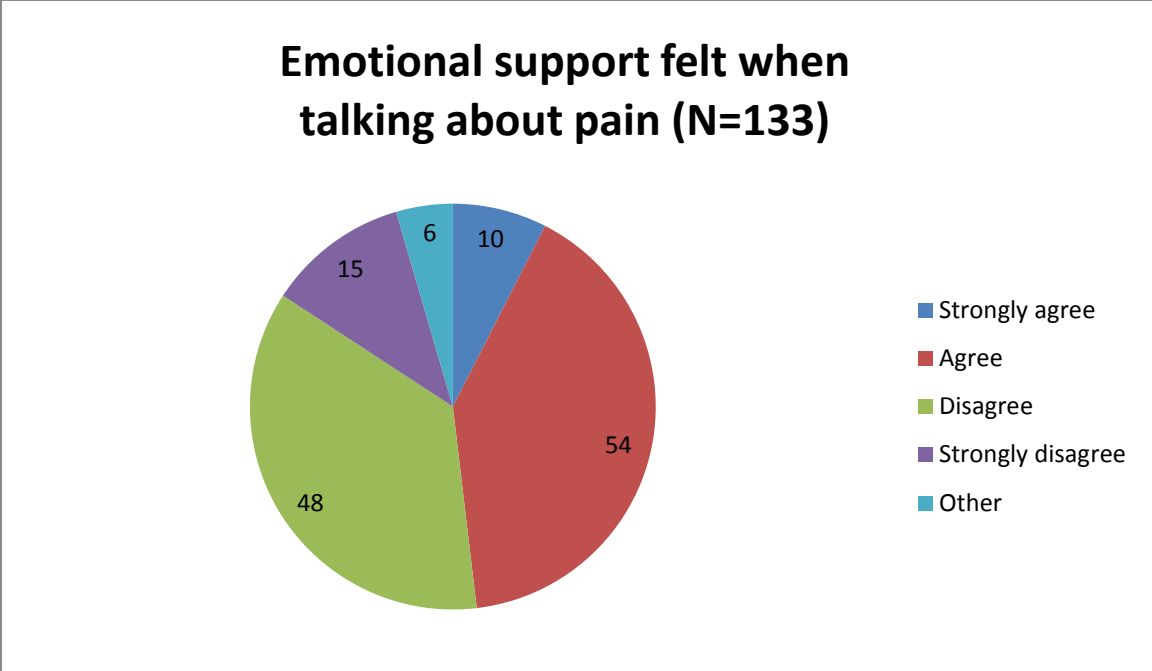
**Figure 19. Perceived Interest in Learning About Chronic Pain Experience**



Yet despite this perceived disinterest others have in learning about their chronic pain experience, respondents indicated they feel emotionally supported when they talk about their pain. A majority of respondents (51%; N=64) indicated feeling emotionally supported when they talk about their pain, suggesting there is therapeutic value to pain communication. Again, audience is a key determinant for the supportive worth. Textual answers provided by six respondents indicated a large determinate of their emotional value depended on with whom they talk. Spouse, friends and extended family were noted to provide emotional support whereas health care providers did not. Results are shown in Figure 20.

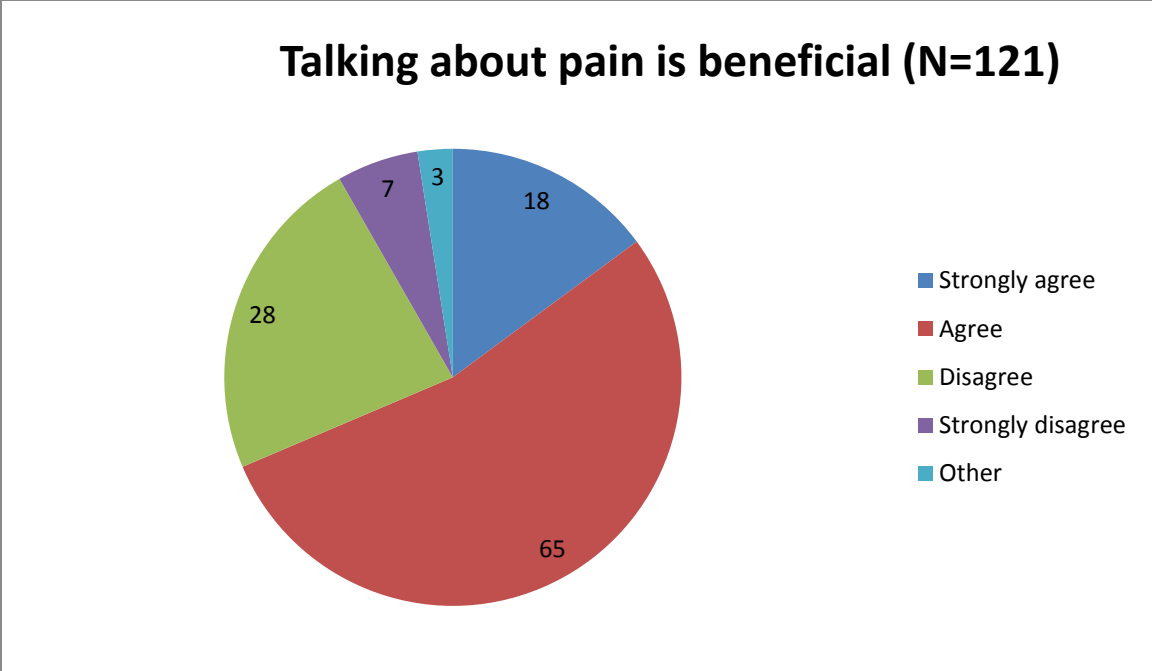
Respondents commented in their own words:

- “When I talk to my husband, yes. When talking to Dr.’s, no.”
- “To family yes, others no.”
- “Chronic pain is hard to sympathize with when needs are not getting met. I can't share a bed with my husband.”
- “I've found talking about it too much lessens the helpfulness as it starts to emotionally drain the person listening and they become less supportive.”
- “Doctors don't hand-hold or empathize.”
- “I feel emotionally supported by my spouse some friend and extended family.”



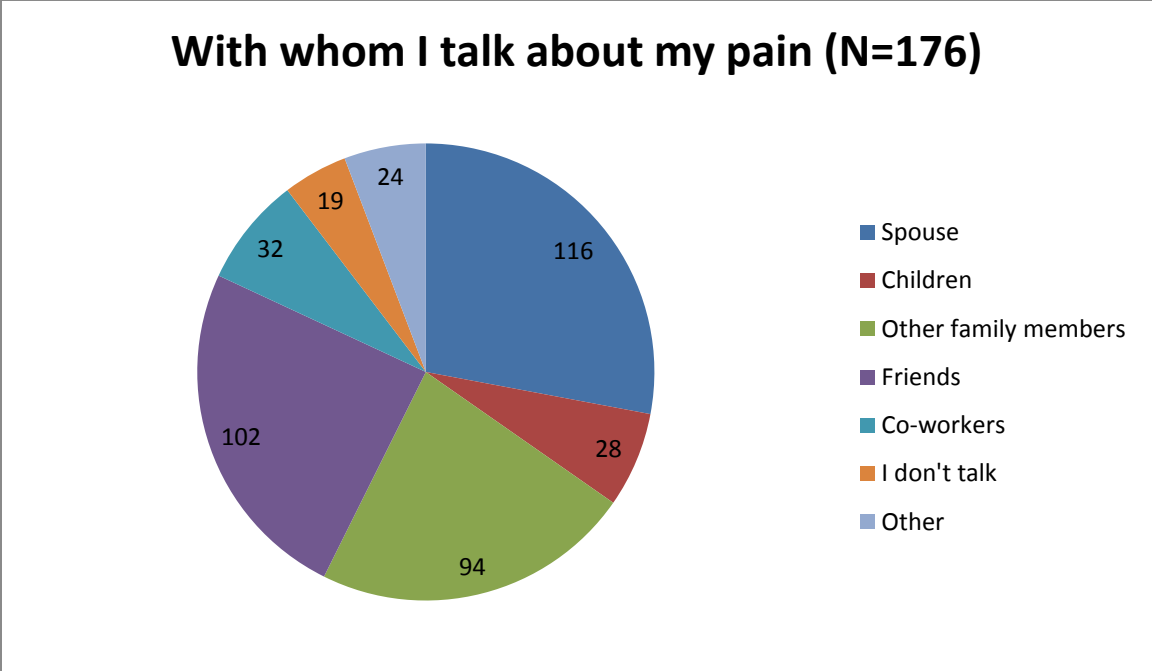
**Figure 20. Emotional Support Perceived When Talking About Pain**

Further, a majority of respondents indicated that they felt talking about their pain is beneficial to them. Seventy percent of respondents designated some form of agreement with the statement that pain communication is beneficial to them versus 30% that indicated some form of disagreement. Of the three respondents writing other responses, two pointed out that it depends on with whom they are talking. Results are illustrated in Figure 21.



**Figure 21. Perceived Benefit of Talking About Pain**

To further attenuate the role of the audience and their emotionally supportive role, a survey question asked respondents with whom they talk about pain outside of their health care provider. Two-thirds of the 176 respondents reported they talk with their spouse (66%; N=116) about their chronic pain. The next most frequent audience members for pain communication were friends (58%; N=102), followed closely by other family members (53%; N=94). There was a large gap between the next identified audience, that of co-workers (18%; N=32) and children (16%; N=28). Eleven percent (N=19) of respondents said they “don’t talk.” Of the 24 respondents who wrote in their own answer, four (N=4) indicated they talked to their boyfriend with one indicating domestic partner; four (N=4) mentioned support groups or pain management groups, and four (N=4) more specified online forums or communities, including Facebook. Two (N=2) respondents indicated they spoke with mental health professionals and one (N=1) mentioned a pastor. Results are illustrated in Figure 22.



**Figure 22. Audiences for Pain Communication**

Workshop writing responses correlate with this survey data and attest to the communication preference of family and friends when individuals with chronic pain talk about their pain. When participants were asked to write out their pain plan (Week 4) to share with their spouse, family members or care takers, trends of with whom participants disclosed their pain were revealed. Many participants acknowledged how rarely they talk about pain with their family.

- “Gulp...this brings tears to my heart...as I can’t share my pain with my family.”
- “My husband is extremely regimented in his daily routine. His nature makes it very difficult to let him know I am in pain and need to change plans or rest instead. He tries so hard to be supportive but when the flare ups are frequent I know he gets frustrated.”
- “I tried to tell my husband about some of my pain. I had some new information from my doctor so I wanted to pass it along to help me process it and get to know what he

thought. After a few minutes he just told me to stop. He told me he zones out when I talk about pain. It's all negative and he just doesn't understand it."

- "My husband and I don't talk about pain. He knows I work hard when I am able."
- "My husband will help out, but I have to ask for help. He is not retired, so he is usually too tired to do much to help. Again, I hate to complain...he has not picked up how I need to have help with the house, etc."
- "The pain has been a part of me for so long, I seldom talk about it."
- "I, too, rarely share my pain. I am good at covering up my pain; very few people know that I always have pain somewhere in my body. I hate to be a complainer and do negative talk."
- "Most of the people that know me, do NOT know that I still suffer daily from pain. I do not talk to my children or friends about it."
- "My ideal pain plan would be that my family would UNDERSTAND but NOT freak out over my chronic pain issue...(only my husband and one child knows my condition out of the pack).
- "For friends that aren't aware of my situation, I often make an excuse as to why I can't attend an event instead of just being fully truthful because I sometimes feel like they don't even want to hear it."

Participants explained they purposely withheld communicating about their pain to protect their family as they didn't want to over-burden others with pain. Shielding others from their pain served to be a protectionist strategy where the sufferer didn't disclose their pain in a sacrificial way. Some participants made concessions for why they couldn't communicate about their pain with their husbands, acquitting them of blame.

- “He [spouse] is a heart patient and I don’t want to stress him out anymore than necessary so I keep my pain to myself most of the time.
- “He tries so hard to be supportive but when the flareups are frequent I know he gets frustrated. I understand—I’m frustrated too!
- “He also wants to be supportive but his job is very, very demanding and many times he is just too tired to help do anything.”
- “I don’t feel I can share my pain with my family...I have kids it would worry and a husband who just can’t handle it.”

These posts reveal how rarely participants talk about pain. For some, pain has become such a consistent factor that the novelty of it has worn off. It is no longer considered newsworthy which causes sufferers to “seldom talk about it.” For others, the act of talking about pain requires too much of an emotional investment. As one participant shared,

“At the end of the day, when I have a few minutes with my husband to talk, pain is at the bottom of the list. There is just too much else going on in our busy lives. It’s like I don’t have any more emotional dollars to spend to talk about my pain.”

This post demonstrates the emotional toll talking about pain can have for sufferers. It is an emotional transaction for both the speaker and the listener, and by applying an economic lens to it sometimes the cost/benefit ratio does not make it profitable to talk about it. There is little value to the emotional currency of pain communication.

The perceived low stock of pain communication influences disclosure practices. Even in an intimate relationship such as marriage, many participants noted they do not disclose their pain to their husbands. Their language also shows the extent that they try to make concessions for their husbands’ reactions by referencing how much and how hard they work, how tired they are.

These statements reinforce (Werner and Malterud, 2003) findings that show that participants are perceived as whiners and complainers. They validate the perceived stigma and negativity associated with talking about chronic pain that Jackson (2005) discussed.

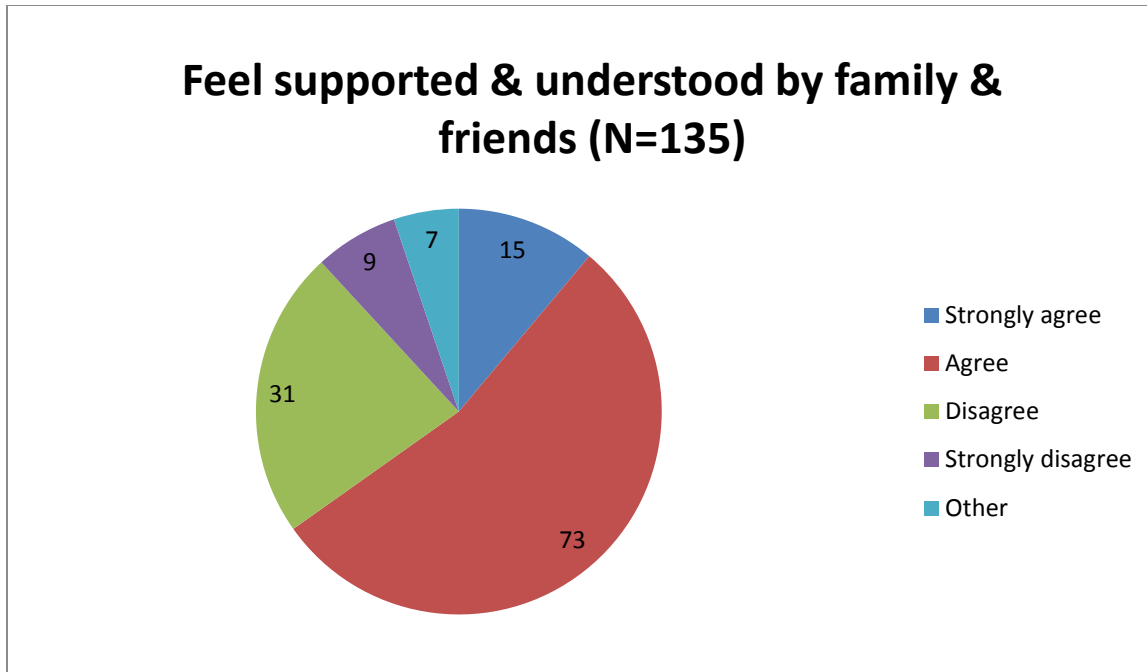
Additionally, when participants had to craft a pain plan consisting of instructions for how they would prefer to be treated when experiencing a pain flare-up, participants singled out tasks for family and friends. The frequency in which family and friends were mentioned attests to their acute role they play in the sufferer's outcomes.

- “My family would ask what tasks I needed to be free of that day.”
- My family would help me with little things that require painful movements without complaining.
- “My family and friends would not WORRY about me or make negative or frightful prognostications....just give me grace and extra help when I need it and don't treat me like a cripple.”

The data illustrate that family and friends are the likely recipients of pain disclosure. In light of Maguire and Pitceathly's (2002) finding which shows providers' are reluctant to inquire about their patients' social and emotional impacts and DiMatteo's (1998) research that indicates the demands of medical training suppress providers' empathy, patients may be increasingly turning towards family and friends to satisfy their need for emotional support. This trend has backing with other survey results which showed respondents felt more support from family and friends, than from health care providers, when they talked about their pain.

When pain communication occurs with family and friends, individuals with chronic pain feel supported and understood. Two-thirds (N=67%: N=88) of respondents designated some form of agreement regarding feeling supported and understood when talking about pain with

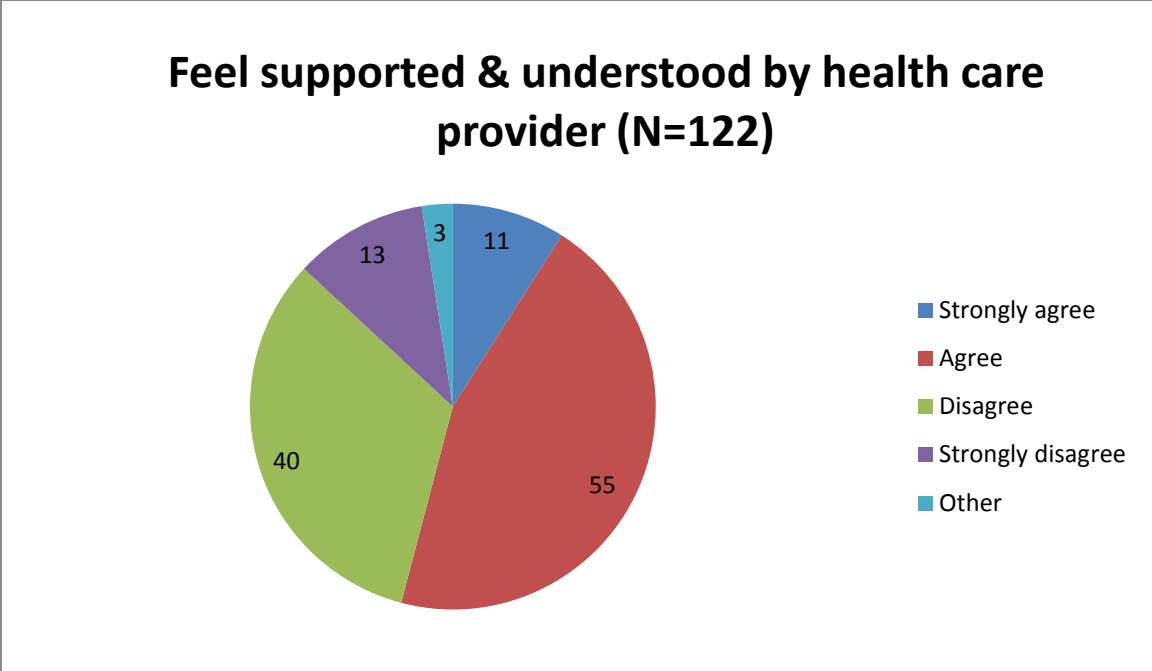
family and friends compared to a third (31%; N=40) of respondents who indicated some form of disagreement. Of the seven textual answers provided, three conveyed that friends also in chronic pain make the best audience as they “give empathy; others perceive you as a freak!” Two textual answers delineated between the difference of support and understanding: “supported, yes, understood, no.” Results are illustrated in Figure 23.



**Figure 23. Perceived Support from Family and Friends**

Comparatively, a little over a half (54%; N=66) of respondents indicated some form of agreement with the same question when it specified health care professionals as the audience. Forty-four percent (N=53) indicated they did not feel supported or understood when they talked about their pain with their health care provider. Results are illustrated in Figure 24.





**Figure 24. Perceived Support from Health Care Provider**

**Concluding Remarks on Audiences’ Influence on Communication Preferences**

Overall, these findings highlight the importance of audience and show the differences in communication preferences individuals with chronic pain have when communicating about pain. They determined a heightened role family and friends play in the care network. The relationship between audience and emotional support correlates with Belenky et al.’s notion that the ability to attend to another person and to relate to them is the basis for the position of constructor of knowledge as it helps to establish communion with what they are trying to understand and facilitates the social construction of knowledge. Accordingly, empathy is “a central feature in the development of connected procedures for knowing” (1986, p. 143). Symbolic interactionism put forth by Mead (1934) and the symbolic-interpretive furthered by Poole et al. (2004) highlight the role the family environment plays on the individual. As Ballus-Creus et al. (2013) determined,

social networks and interpersonal relationships have a large sway on an individual's response to pain.

These findings reinforce the role family and friends play in providing therapeutic communication and accentuate the need for them to foster empathetic responses. Survey data attest to the emotional value gained when individuals with pain communicate about their pain and reveal their desire to receive more empathy upon their disclosure. When family and friends respond with empathy they are encouraging more disclosure and thus, a positive cycle of open communication and emotional support can be created.

RQ 3: How does the gender of an individual suffering from chronic pain influence communication preferences with medical providers?

To examine the overall data for gender specific preferences, an independent samples t-test was conducted to compare how men and women, the independent variable, prioritize types of communication they would like to receive from their health care provider, the dependent variable. Respondents ranked the importance, on a scale of one to five, for five types of communication including 1) information about their chronic pain condition, 2) information about their treatment plan, 3) support for their emotional well-being, 4) empathy for the debilitating impacts of chronic pain, and 5) an opportunity to talk about their pain in their own words.

The null hypothesis is that there is no difference between the types of information and support men and women want to receive from their health care providers. Results from the independent samples t-test show that gender does not influence the types of communication individuals with chronic pain want to receive from their health care provider. See Appendices M and N for descriptive statistics and t-test results. Specifically, there was not a significant

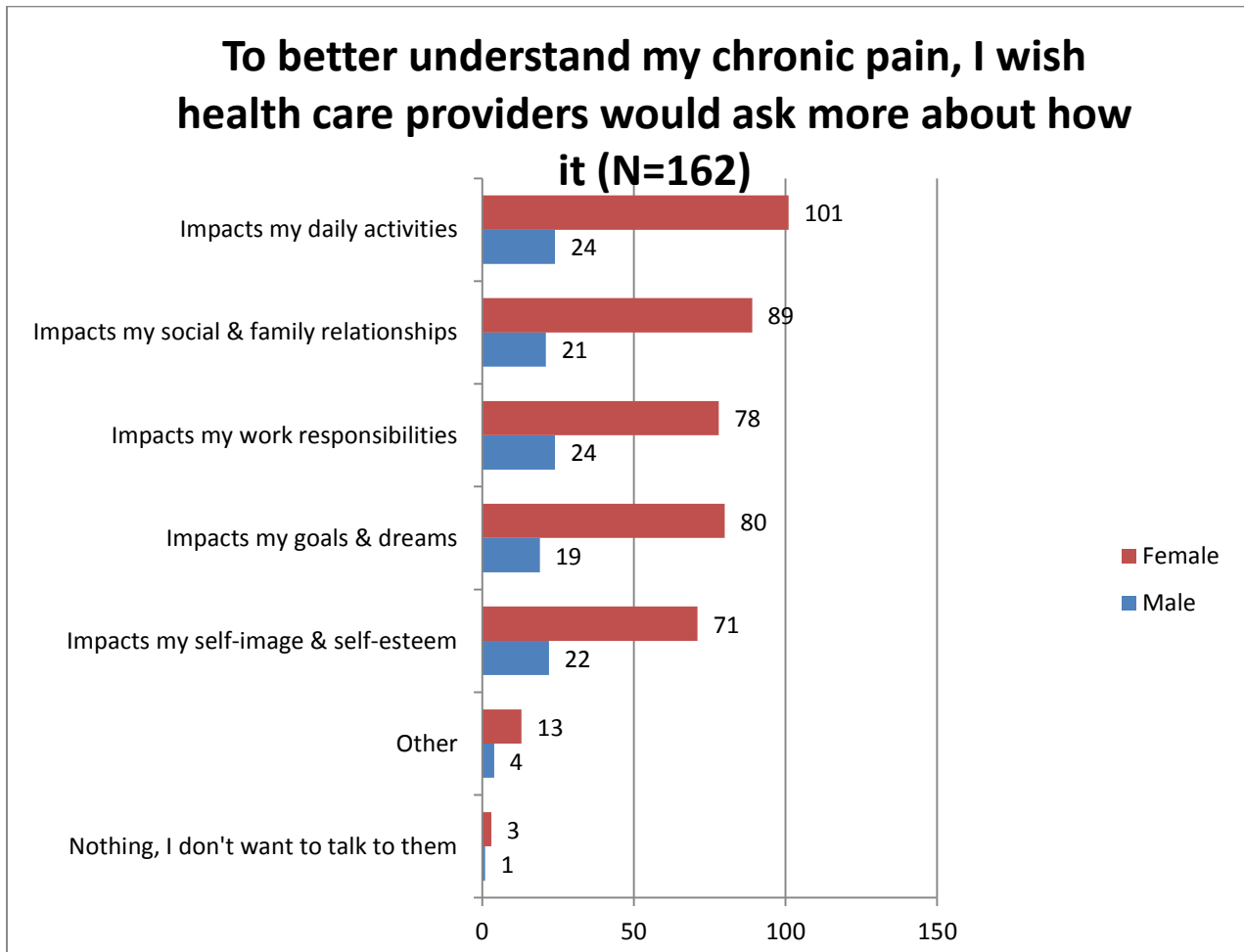
difference in the scores men and women prioritized for receiving information about their chronic pain condition  $t(160) = .47, p < .05$ ; information about their treatment plan  $t(159) = .27, p < .05$ ; support for their emotional well-being  $t(160) = .48, p < .05$ ; empathy regarding the debilitating impacts of chronic pain  $t(160) = .07, p < .05$ ; and opportunity for them to talk about pain in their own words  $t(159) = .84, p < .05$ .

The preferred type of communication from health care providers for both genders was instrumental in nature, where men ranked information about their treatment plan as their number one priority, followed by information about their chronic pain condition. Females had these ranked in reverse order. The opportunity to talk about pain in their own words was ranked third most important for men, whereas women ranked receiving empathy as their third priority. Both genders placed receiving support for their emotional well-being in fifth place.

In general, these findings reinforce what Ong et al., (1995) discuss when they stated patients need cure-centered information to know what is causing the pain as well as care-centered information that allow them to feel known and understood, but Ong et al.'s study did not differentiate for gender. The fact that the t-test results for health care provider preferences were not statistically significant is encouraging because it suggests health care providers do not need to tailor their communication practices to target one gender. The relative similarities among men's and women's mean scores indicate congruence in their communication priorities.

Further gender differences were revealed when respondents had to prioritize the types of questions they would like to be asked by their health care provider to better understand their pain. Since respondents could select more than one response option, and the options were nominal, a t-test cannot be calculated yet analyzing group response statistics for gender shows that in order for health care professionals to better understand their impacts of their chronic pain,

men prioritized receiving questions regarding their daily activities, followed by work activities and self-image. Women similarly ranked inquiries pertaining to daily activities as their top choice but ranked questions pertaining to social and family relationships and goals and dreams as their top question preferences. Results are shown in Figure 25.



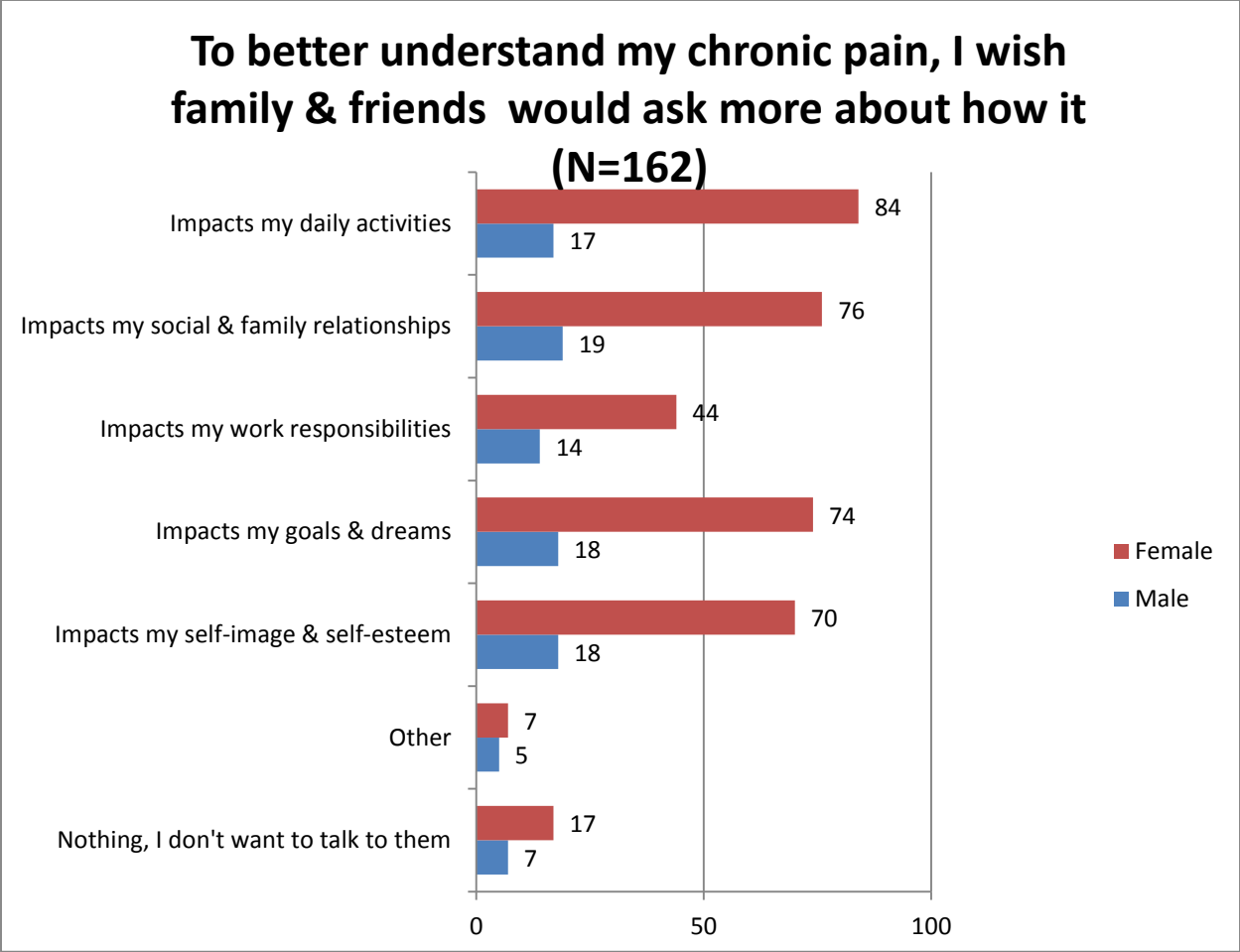
**Figure 25. Preferred Questions from Health Care Professionals**

RQ 4: How does the gender of an individual suffering from chronic pain influence communication preferences with non-medical providers?

### **Gender Differences for Pain Communication with Family and Friends**

When the same question was asked but the audience changed from health care providers to family and friends, the communication preferences drastically change. Not only were the types of communication valued differently, but there were noteworthy effects for gender with t-values showing statistically significant findings among the results that are not likely due to chance or researcher error. Specifically, there were significant differences in the scores men and women prioritized for receiving information about their chronic pain condition  $t(160) = .04, p < .05$ ; empathy regarding the debilitating impacts of chronic pain  $t(160) = .05, p < .05$ ; and opportunity for them to talk about pain in their own words  $t(158) = .00, p < .05$ .

For family and friends to better understand the impacts of their chronic pain, men prioritized questions pertaining to social and family relationships, self-image and goals and dreams as their top three preferences. Women preferred to be asked by family and friends questions relating to daily activities, social and family relationships and then goals and dreams. Results are shown in Figure 26.



**Figure 26. Preferred Questions from Family and Friends**

The data determined women have a high desire (4.49 out of 5) to receive support for their emotional well-being when they are communicating about their pain with family and friends, followed closely by empathy regarding the debilitating impacts of chronic pain (4.48). These findings illustrate the strong need women with chronic pain have for receiving emotionally supportive communication from family and friends and highlight a potential gap in their treatment plans. The longing for emotional support highlights the emotional toll that living with chronic pain has on individuals. The examination of the differences in which men and women express and gain validation for their pain previously discussed underpins this statistically significant finding.

## **CHAPTER FIVE**

### **DISCUSSION**

This research adds momentum to the burgeoning interest in delivering health care that places patient preferences at its center. It provided a unique opportunity to better understand the variables influencing communication preferences of individuals with chronic pain using both qualitative and quantitative approaches. These results suggest that gender and audience have a large influence on communication practices when it comes to communicating about pain. Both the discourse analysis of the online writing workshop responses and the survey data suggest that women with chronic pain desire more emotional support. The practice of triangulating the data sets bestows a sense of confidence with the findings as it reduces bias inherent in a particular data set and discouraged eliminating a data set for ease of analysis (Anfara, Brown, & Mangion, 2002).

When individuals with chronic pain converse with health care providers about their pain, this study concludes that chronic pain patients place greater importance on receiving instrumental information, such as information about their condition and treatment plan, as well as emotional support, such as empathy and the freedom to talk candidly about pain in their own words than men. When conversing with family and friends, individuals with chronic pain prefer more emotional support in the form of care for their well-being and empathy regarding the debilitating impacts of chronic pain.

Results from this research conclude the dual need for individuals with chronic pain to receive information as well as emotional support and highlight the complexity in trying to determine what types of communication constitutes as therapeutic. As Roter, Hall and Katz (1987) discussed, there is some inherent overlap as informational communication can fulfill an emotionally supportive function. The fact that both cure-centered and care-centered findings were prioritized aligns with previous studies that report the types of communication patients prefer is inconclusive (Roter, Hall, & Katz 1988), and illustrates the inability to operationalize the definition of what types of communication constitute as therapeutic. However, an examination of the way both men and women ranked their preferences may help to refine our understanding of pain communication. It is worth noting that both genders had similar mean averages for receiving emotional support and empathy, but women greatly prioritized an opportunity to talk about pain in their own words. These differences in findings demonstrate the way audience has a large bearing on pain disclosure and communication preference. They also suggest partialities within genders but further research is needed to indicate if these differences are statistically significant.

### **Clinical Value of Patient Communication Preferences**

Understanding patients' preferred communication styles has great clinical value for health care providers. In the context of decision making research has shown that patients are more likely to actively participate in their care, make wiser decisions, share a common vision with their physicians and abide by treatment directives if they are informed (Epstein et al., 2004). Haynes et al. (2002) developed a participatory model for decision-making with patients that accounts for the complexity of synthesizing clinical findings with research evidence and patient preferences, beliefs, and values. (See Figure 27).

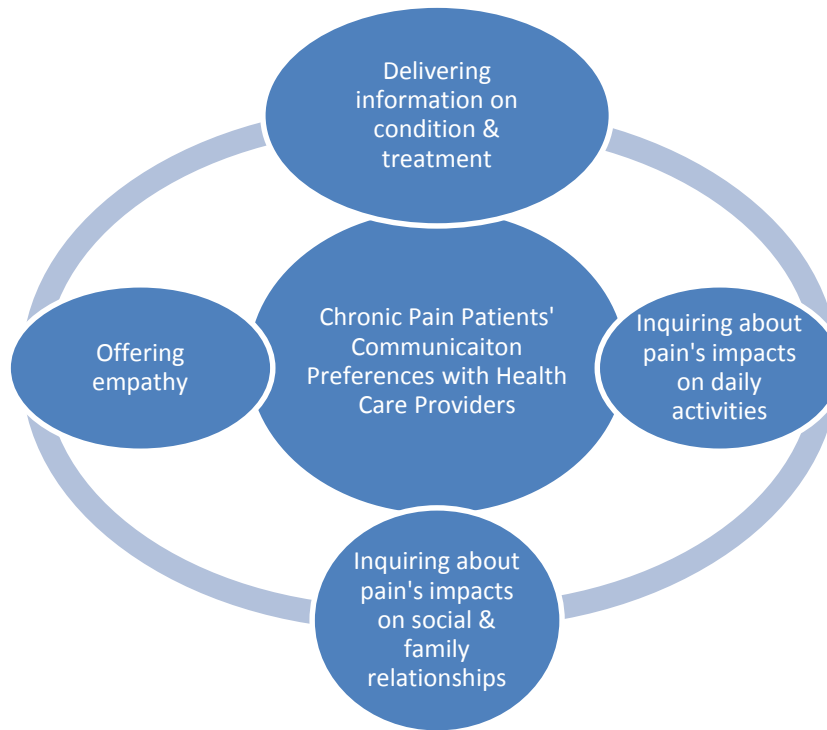




**Figure 27. Model for Evidence-Based Decision Making (developed by Haynes et al., 2002).**

In order for patients to actively be involved and take ownership of their treatment, they must be included in the decision-making process, but what is unclear is how to convey evidence to patients so that they can understand the information and make wise decisions (Trevena et al., 2006). Epstein et al. (2004) claim there is a paucity of research to guide physicians on how to communicate evidence to patients so they can make informed decisions. Trevena et al. (2006) tried to determine what effective strategies there are for eliciting patient preferences about evidence, but found limited available evidence in their systematic review and determined that preferences vary for each individual and are better elicited by attending to patient values.

The research results from this study are clinically useful by adopting Haynes (2002) model to the context of chronic pain communication with health care providers and inserting research findings into the “Patients’ Preference and Actions” circle. An expanded model for attending to patient preferences for chronic pain patients is demonstrated in Figure 28.



**Figure 28. A Model for Patient-Centered Communication**

Starting at the top of Figure 28 and then moving clockwise, this model identifies the sequence of preferred communication exchanges patients would like to have with their providers. Specifically, the this study’s findings determined that both men and women suffering from chronic pain want to receive information on their chronic pain condition and treatment plan when communicating with their health care providers. This cure-centered communication preference can guide the communication exchange in a clinical setting and help providers focus on diagnosis and treatment procedures.

Yet for patients to feel that their health care provider understands more than their physical sensations of pain, but how living with chronic pain impacts them as a person in myriad ways, they would like their health care providers to ask open-ended questions focusing on how pain impacts their daily activities and their social and family relationships. These inquiries prioritize patients’ own subjective knowledge, can deepen the communication exchange between

provider and patient, and facilitate personal disclosure. By allowing patients to talk in their own words and by responding with empathy providers are bridging the gap between themselves as physicians and their patients as "othered" individuals. Moreover, the questions can help patients process their emotions and reflect on experiences that affect their mental, emotional, social, professional, psychological, and spiritual well-being. As a result, a more holistic account of their pain can be painted which may increase understanding.

Finally, in response to these replies, patients would like providers to offer empathy. The response is crucial because if patients do not feel emotionally supported after disclosing of their pain, they may feel more isolated and invalidated (van Hooft, 2003; Good, 1992; Werner, Isaksen & Malterud, 2004; Jackson, 2005). It is important to view the patients' emotional disclosures as a means to build rapport and providers must be cognizant of the emotional investment inherent in pain communication (Cano, 2010). Empathic responses can validate the patients' emotional disclosures and offer support for the debilitating impacts of chronic pain.

When patients feel they are receiving their desired information about their condition and treatment as well as empathetic responses in return upon their pain disclosures, results from this study concluded that patients feel validated and supported. In turn, this support can translate into patient satisfaction and improved rapport with their health care providers which can help involve patients in the decision-making process and gain their buy-in into the prescribed treatment plan. As previous research has demonstrated, patients who feel listened to report higher patient satisfaction and have higher treatment adherence (Tongue, Epps, & Forese, 2005; Wright et al., 2003; Maguire & Pitceathly, 2002). In this way, the model for patient-centered communication is a mechanism to improve patient satisfaction and adherence by tailoring communication practices

with chronic pain patients so that they feel validated, supported and actively involved in health care decisions.

### **Pain Communication as Action**

Examining the data with a gender lens revealed that women specifically value receiving support for their emotional well-being and empathy when they communicate about their pain. For family and friends to better understand the impacts of their chronic pain, men prioritized receiving questions pertaining to social and family relationships, self-image, and goals and dreams as their top three preferences. Women preferred to be asked by family and friends questions relating to daily activities, social and family relationships and then goals and dreams.

Of the findings that have statistical significance, two out of the three communication preferences are care-centered and emotionally supportive. Specifically, women's desire for more support for their emotional well-being and empathy when communicating with family and friends highlights the heightened role family and friends can play in their overall health outcome. Providing opportunities for them to talk in their own words and listening attentively can go a long way in fostering a supportive environment.

Given the disproportionate incidence rate of women experiencing chronic pain and facing a greater risk of developing a pain condition (Elliot et al., 1999; Edwards, 2013) these communication preferences unique to women have great value. Women reportedly express more pain and higher severity and duration of it (Akhani et al., 2014; Silver, 2004; Unruh, 1996). Of further importance, since there are nearly twice as many male physicians as female physicians, gender communication practices play a heightened role as female patients are most likely to communicate to a male physician (Kaiser Family Foundation, 2014).

Additionally, women's communication preference to have more opportunities to talk about pain in their own words with family and friends statistically stood out. With a p value of less than .01, this finding helps to determine that pain communication has therapeutic value by showing how individuals with chronic pain, particularly women, feel supported when they talk about pain and place great importance on receiving empathy and support for their emotional well-being. However, women were more likely than men to perceive others are not interested in learning about their pain.

Therefore, the problem is not that pain is inexpressible. Findings have shown that contrary to expectation, pain is communicable. Nearly two-thirds of survey respondents indicated that they feel they can adequately communicate pain (See Figure 18). What is missing is the interest. Over eighty percent of survey respondents perceived a disinterest from others in learning about their chronic pain (See Figure 19). Hearing about others' pain is not an easy subject to take interest in as listeners are apt to feel helpless and frustrated in their futility of fixing it or making it go away. This research attests to the lack of communication individuals with chronic pain have with their spouses and friends regarding their pain. Yet according to Reis and Shaver's (1998) interpersonal process model, when one self-discloses emotional material and is met with the partner's empathic and validating responses, intimacy is developed. Cano (2010) claims that verbal communication about one's thoughts and feelings about pain are attempts to disclose emotion, recruit emotional support and build intimacy. In this way, pain communication can be seen as an attempt to build closeness.

In light of how rarely individuals with chronic pain communicate about their pain with their family and friends, it is clear that sufferers are selective about with whom they try to build intimacy. Trust and rapport are necessary precursors to this disclosure. However, the ambiguity

of the reception to this emotional disclosure may be the source of the reluctance to communicate about their pain. As noted by Fruzzetti and Iverson (2004) emotional validation and empathic responses enhance the emotion regulation process for both partners as they process stressful stimuli such as persistent complaints of pain and ongoing medical issues. Yet, hostile or antagonistic responses indicate rejection and disregard for the sufferer and disrupt emotional regulation.

What is needed is a new conceptualization which views pain communication as strategic action; rather than interpreted as complaining, pain communication needs to be understood as emotional disclosure as a method to build intimacy. As recipients of this self-disclosure, family and friends need to offer validating responses that enhance intimacy, promote further disclosure, and foster healthy emotional regulation. A first small step to invite this communication can be asking questions that enable sufferers to talk in their own words about its impacts. This type of pain communication does not focus on factual or pragmatic information but what van Hooft (2003) refers to as intersubjective disclosure of vulnerability and emotional disclosure.

This study brings to light that rather than pain hindering communication, it can serve as a trigger for closeness. Pain's intensity causes sufferers to be self-preoccupied by its effects and compels them to action, oftentimes forcing the sufferer to rely on others, medical or non-medical providers, for help. In this way, pain amplifies interpersonal communication as there is urgency in communicating with others. This change in thinking from considering pain as an impediment to communication to one that is a prompt for communication is a substantial paradigm shift. Yet pain can be viewed as a natural prompt for communication and a means to build intimacy, if audiences are willing to listen.

## **Understanding the Need for Emotional Support**

While it is clear individuals with chronic pain desire more care-centered communication practices, specifically desiring emotional support for their well-being and empathy regarding the debilitating impacts of chronic pain from family friends, the discourse analysis helps to *explain why* this emotional support is sought. Within the interpretive repertoire of ‘pain as discredited self’ writing workshop responses pertain to the invisible nature of participants’ pain and the efforts they make to manifest it; the effort they discuss confirms that credibility, legitimation and validation are central characteristics to the experience of living with chronic pain. By highlighting the emotional toll that living with chronic pain has on individuals these findings reinforce the definition put forth by the International Association for the Study of Pain (1994) which states that pain has both sensory and emotional modalities.

As discussed, credibility and performativity are central tenets to the experience of conveying chronic pain (Jackson, 2005; Ware, 1992; Birk, 2013). The desire for more support for emotional well-being may be warranted due to the work women must undergo to be seen as credible by the medical community (Kleinman, 1988, 1992; Werner et al., 2004; Johansson et al., 1996; Birk, 2013) and to retain a sense of control (Skuladottir & Halldorsdottir, 2008). Women are more likely to be regarded as hypochondriacs than men and their pain accounts are more likely to be dismissed (Ford, 1995). To have their pain believed, women must work to perform their pain and this performance requires effort and strategy (Werner & Malterud, 2003; Nguyen et al., 2013). If despite their labors they do not gain validation by the medical community female patients feel undermined, misunderstood, doubted, rejected, belittled and ignored (Wendell, 2006; Werner & Malterud, 2003).

The invisible nature of pain combined with its unverifiable characteristic puts the onus on the sufferer to both be a credible subject as well as a compelling performer. The efforts that sufferers go through to demonstrate their pain, coupled with the dismissive responses that sufferers experience gives testament to the need for physical representation (Kleinman, 1988, 1992; Skuladottir & Halldorsdottir, 2008; Werner et al., 2004; Asbring & Narvanen, 2001). Due to the large emotional expenditure involved in their effort to gain validation once they have communicated their pain, it is not surprising to learn women want to receive emotional support for their well-being in return.

Participants discussed the invisibility of pain presents them with a choice to reveal or conceal their pain identity and results show how frequently they hide their pain, even among spouses, family members, and friends. The infrequency in which they share their pain conveys the extent of pre-meditation that goes along with the disclosure. Due to the difficulty participants admitted in articulating their pain and the disinterest they perceived others to have in hearing about their pain, participants shared “they hadn’t figured out how to broker that conversation.” In other words, pain communication doesn’t just happen. Prior to disclosure, there is strategic decision-making where pain sufferers have already weighed professional and social risks and consequences; given the weight associated with the choice to disclose, an emotional investment has been made. Therefore, an emotional response is sought.

Additionally, the finding that revealed the scarcity of pain disclosures with spouses and other family members for fear of burdening or stressing them suggests that participants are aware of the emotional weight their pain communication has on their audience. When individuals with chronic pain are emboldened and empowered to share their pain, it indicates a level of trust and



rapport. In return, there is a yearning to receive emotional support, empathy and an opportunity to talk more about their pain.

### **Identifying Women Specific Communication Preferences**

Previous research has shown that patients are more likely to develop a therapeutic relationship with their providers if the providers use words which convey empathy and respect (Swain, 1997). Empathetic responses convey the provider is listening and recognizes the worry, concern or other difficulties the patient has experienced (Gifford, 2013). On the contrary, flippant or patronizing comments can inhibit the patient from opening up and sharing more information (Edwards et al., 2001).

Women's aspiration to receive empathy is congruent with previous research on chronic pain patients. Ha and Longnecker (2010) discuss how the ability of physicians to show empathy to their patients is one of the most powerful ways to reduce feelings of isolation and provide validation to their feelings and thoughts. Beck, Daughtridge and Sloane (2002) identified several verbal behaviors that are valued by patients, including empathy, reassurance and support, and patient-centered questioning techniques and Teutsch (2003) highlighted the need for providers to show compassion and empathy to their patients. Empathy is also noted as a defining quality of delivering patient-centered care in the twenty-first century (IOM, 2001).

What this research finding adds to the existing literature is that it examines the effect of gender on chronic pain communication preferences and isolates women-specific preferences. Knowing that the need for empathy is largely expressed by women enables a more refined communication approach when communicating with this audience. While this research is not discouraging showing empathy to males who experience chronic pain, this finding highlights a need that women may not directly express. Taken together with writing workshop response,

when women disclose their pain, these findings suggest women want an empathetic response, not one of information or advice.

### **Pain's Impact is Outside the Body**

To cater toward patient-centered care and help support women with chronic pain, family and friends can ask open-ended questions about sufferers' health to allow women the opportunity to speak freely. As noted in the writing workshop responses, the way women may talk about their pain may be less about their physical symptoms and more about the way pain impacts them such as having a disordered house or having to cancel plans. Additionally, the visible signs of clutter reinforced their inability to perform household chores which increased their anxiety, which in turn aggravated their pain.

This research calls for more attention to be directed less on the corporeal body of the individual with chronic pain for indicators of pain and more on their home and behavior. It changes the biomedical gaze of focusing the medical lens on the interior of the body and instead places emphasis on an individual's functionality and relational capacity. It puts forth the argument to expand the concept of pain management to encompass one's external environment. By so doing it frees the sufferer from having to reproduce pain and offsets the dismissal sufferers receive from the medical community (Kleinman, 1988, 1992; Skuladottir & Halldorsdottir, 2008; Werner et al., 2004). Without the expectation of performing pain, sufferers are relieved from having to recall and reproduce an abstract thing and feelings of abrogation and invalidation may be diminished (Wendell, 2006). Further, attending to the home environment places focus on the visible evidence of pain and the tangible evidence of inability and clutter may alleviate disbelief and skepticism. By taking into account assessments of patients' physical environments,

relationships, work responsibilities, and personal goals a more holistic understanding of pain's impacts are understood.

The ability to recognize indicators of pain and attend to non-verbal communication can help identify when an individual with chronic pain is experiencing a pain flare-up and attend to them without the sufferer exerting any emotional energy in trying to communicate it. This finding can minimize effort and maximize care but it is hinged on the family and friends having awareness of and interpreting the pain behavior. Educating those in the sufferer's care network on these potential indicators can be a powerful tool in delivering supportive care.

### **Institutional Communication: Self-Protection Communication**

There is a strong relationship between language and social context and Halliday (1978) claims it is necessary to acknowledge that any particular account is intimately influenced by the circumstances of its production. Research has shown that communication in formal institutional settings, such as a clinical office visit, are governed by task-oriented behavior, that the order of participation is fairly rigid, and that the kind of communication interaction is limited, almost pre-allocated (Drew & Heritage, 1992). When health care providers inquire as to their patients' symptoms, research indicates they want specific and detailed accounts to help them establish the right diagnosis, not emotional responses (Ong et al. 1995).

Moreover, the positivist stance toward language adopts a view where language is representational, objective and a neutral medium (Nastasia & Rakow, 2010). In this perspective, the language used is separate from the speaker in that the speaker's values, attitudes and biases do not influence the accounts provided (Katz, 1976; Price & Cheek, 1996). Therefore, what is valued are objective descriptions and specificity that can be applied to observation, experiment and comparison (Keat, 1979). Emotions and affective responses are not typical in scientific

reports or scientific language where the emphasis is on factual, objective information (Knisely, 2009).

As research has shown, patients who report good communication with their providers are more inclined to follow prescribed treatment and feel more invested in their treatment plan (Maguire & Pitceathly, 2002; Hall, Roter & Rand, 1981; Roter, 1983; Tongue, Epps, & Forese, 2005; Wright et al., 2003). Yet research has also pointed out that providers are reluctant to inquire about the social and emotional impacts of patients' problems (Maguire & Pitceathly, 2002). Previous research has demonstrated that when patients express emotional responses to their pain, but are not met with empathetic responses they may perceive disinterest or lack of care from their provider, (Beck, Daughtridge, & Sloane, 2002). Further research has shown perceived provider apathy may deter patients from willingly sharing their concerns (Schmid Mast, Hall, & Roter, 2008) and negatively impacts health outcomes (Beck, Daughtridge, & Sloane, 2002).

This research, applied to the writing workshop responses which conveyed heavy use of emotions when participants were asked to describe their pain, highlights the tension that exists when a descriptive account is asked and an emotional response is given. The perceived lack of interest from providers may explain the survey findings that determined individuals with chronic pain prefer information about their condition and treatment over emotional support from health care providers. In particular, when individuals open up about their pain and reveal personal hardships to their provider, but don't receive an emotional response in return, they may feel more exposed and susceptible. By focusing the communication exchanges on instrumental behavior with their health care provider, individuals with chronic pain may be protecting themselves against disappointment and vulnerability.

While further research is needed to confirm this working hypothesis, it is worth considering that patients, especially women, are cognizant of the perceived stigma that women are overly sensitive and exaggerate their pain accounts (Hoffmann & Tarzian, 2001; Calderone, 1990; Unruh, 1996). Research has documented that female patients are less often referred to specialists and more likely to be given sedatives than male patients (Calderone, 1990; CDC, 2013). Female patients may purposely filter out their emotional information with their provider, including their desire for emotional support, as a means to maintain their self-esteem and in attempt to counter the ‘histrionic female’ stereotype (Fishbain et al., 1986). These considerations offer alternative explanations of the finding that shows patients prefer instrumental information from their health care providers.

The lack of emotional support received from health care providers magnifies the need individuals with pain have to receive emotional support from family and friends. While it is unrealistic to expect health care providers to provide emotional support and establish a rapport with all of their patients, it could be feasible for them to encourage their patients to seek out emotional supportive therapies. Possible recommendations would be to encourage patients to seek out online support groups or inquire into local chapters of chronic pain support groups.

### **Benefits of Computer Mediated Discourse**

The online writing workshop was effective in providing a place for creative engagement where the important work of validation and normalization occurred. The writing workshop prompts allowed participants to answer in their own words, but also on their own time. Previous literature has focused on analyzing provider-patient communication interaction patterns where abbreviated office visits and unequal roles tainted the communication process (Maguire & Pitceathly, 2002; (Dugdale, Epstein, & Pantilat, 1999). The non-medical context played a critical

consideration as computer mediated communication in a closed group leveled the playing field, where there was no hierarchy among participants.

Given the structural constraints of language to represent abstract ideas, participants overcame the void by creating their own linguistic techniques. Maria Bakardjieva (2005) posits technology as language, with its own system of norms and codes, yet also possessing openness to change. The combination of computer key strokes allowed participants to express themselves online that would not be possible during face-to-face communication. Specifically, the use of emoticons helped to convey emotions and was used frequently enough throughout the workshop that they became their own genre. For example, one participant was giving affirmation to another's post and she responded by inserting two smiley faces to convey her feelings of appreciation.

“awww, that is so kind and encouraging :) ty for those lovely words :)“

Further, timing was an important factor as participants had a week to reflect on the writing prompt, craft their response, and receive feedback on it. The leisurely pace of the workshop allowed participants to choose a convenient and pain-free time to engage and tailors to Castell's (2002) concept of the space of flows. In the ebb and flow of pain cycles participants could focus on writing about the experience of living with pain without pain obscuring their language or fogging their memories. As a result, participants' communication may provide a more realistic portrayal of the way pain impacts them as their communication did not have the urgency as it does when communicating with health care providers where pain alleviation is the focus. Unlike in a medical context, pain, its locale, length, and description were not the focal point.

## **The Power of Disclosure via CMC**

This study demonstrated the power and utility of using computer mediated communication as a viable method to recruit participants and deliver an intervention. The relatively risk-free, anonymous setting of the online workshop enabled participants to express themselves candidly. Whether it was through writing via the online workshop or through open-ended response on the survey, the opportunity to communicate in their own words proved to be of value and may be important for achieving catharsis among those who suffer from chronic pain, a stigmatizing illness or condition.

Participants were willing to disclose private sentiments. Surprisingly, some participants revealed they had never talked about their chronic pain with their family. As one participant wrote in response to formulating her pain plan so that loved ones would know how to better care for her when experiencing a pain flare-up, she posted “*GULP....this brings tears to my heart....as I can't share my pain with my family.*”

This disclosure sparked another admission. Another participant shared that she tried to tell her husband about her pain:

*I had some new information from my doctor so I wanted to pass it along to him to help me process it and get to know what he thought. After a few minutes he just told me to stop. He told me he zones out and stopped listening when I talk about pain. He just doesn't understand it and can't take it.*

These findings correlate to Ko and Kuo's (2009) study which attests to the power of anonymity and self-disclosure among bloggers who were unable to share their ailments in real world but were emboldened to reveal online. For some participants in the online workshop, this

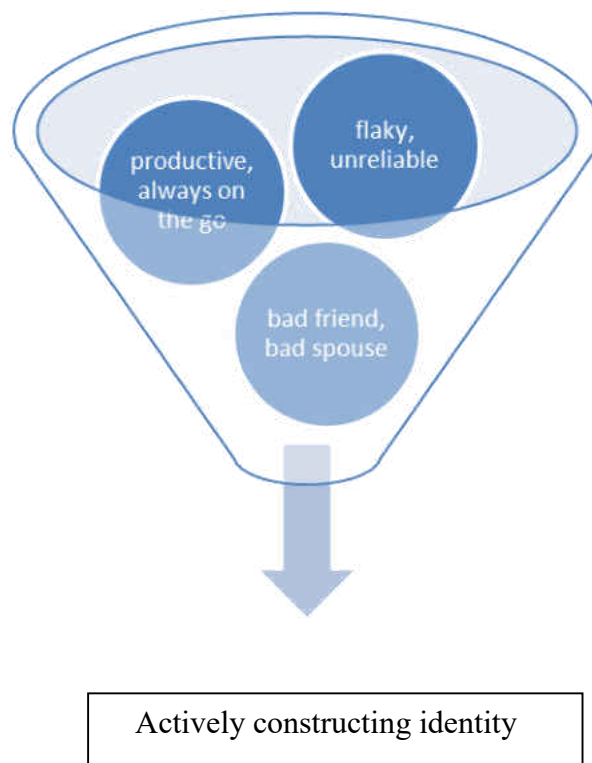
was their first occasion to talk about their pain in a supportive environment. The ability to relate with others highlights the critical need for social support (Ko and Kuo, 2009).

### **Construction of Pain Identity**

Additionally, the selectiveness with which participants choose to reveal their chronic pain identity highlights the fragmented nature of their identity. For individuals with chronic pain, identity has become more about multiplicity than unity. The self-concept of a decentered, fractured and fragmented identity as illustrated in the interpretive repertoire of ‘pain as fragmented self’ works well for individuals with chronic pain as the pain identity is just one persona of many. The online writing workshop served as a site for writing and rewriting the self. In this way, participants are “cycling through”, a computer term used by Sherry Turkle to explain the diverse experiences participants have in moving from real-life persons to on-line personas, between real and virtual worlds (cited in Bell, 2007, p. 41). The ability to split identities and focus on the one that primarily occupies attention affords the opportunity for identity play so that individuals with chronic pain may become someone else online. However, the new identity does not mean deception is at play. Rather, the ability to present oneself differently online than in real life caters to postmodern multiplicity, heterogeneity, and fragmentation (Bell, 2007). In turn, participants are actively producing an identity. Turkle (1995) discusses the therapeutic value of this identity play in cyberspace and its ability for users to cycle through different selves. As participants cycled through their various identities, from that of knowledge receiver in the traditional biomedical model to identity producer in cyberspace, they were empowered. The opportunity to share pain experiences and impacts enabled them to take on a productive role, one in which they were actively contributing to and steering the conversation.



For example, some of the characteristics expressed in this ‘pain as fragmented self’ interpretive repertoire had to do with the disjointed sense of identity caused by the cyclical nature of pain flare ups and then pain free days. Figure 29 exemplifies some of the participants’ attributes. What emerges from this funneling process of identity formation is one which positions individuals with chronic pain as active participants in forming their identity and their choices in presenting certain aspects of it. This idea of choice and agency contrasts with statements expressed in the writing workshop that conveyed a passive stance and lack of control: “I don’t want the fact of my constant pain to define my entire self” and “I don’t want to be identified as Pain Woman.” By acknowledging the influence pain has on constructing one’s identity, individuals with pain can learn which facet of their identity they want to present and to whom. In this way, pain doesn’t have to define them; they are using pain as a means to construct their complex identity.



**Figure 29. Construction of Pain Identity**

### **Power of First Person Perspective**

In trying to answer how communication preferences are influenced by audience and gender, it is important to take into account the results from the writing workshop as this qualitative data provides rich, first person descriptions of the experience of living with chronic pain in participants' own words. Moreover, the design of the writing workshop utilizing Internet technology minimized researcher presence or institutional bias; individuals with chronic pain were able to connect with one another directly from the comfort and convenience of their own home without a researcher interrupting the flow of communication. This casual atmosphere of this research design provided the ability to examine naturally occurring talk within this targeted population. Although strangers were interacting through computer mediated communication, their commonality of identifying with chronic pain fostered a sense of community and familiarity and reinforced my (2013) findings that individuals with chronic pain yearn for more validation and encouragement.

While some of the themes to emerge in the qualitative data reinforce previous research findings such as the invalidation of chronic pain sufferers' and the multi-faceted impacts of pain this study furthers our understanding of the experience of living with chronic pain as it delivers what Thorgaard (2010) argues and prioritizes: first person accounts. For example, while other studies reported nearly two-thirds of chronic pain sufferers have lower quality of life, (Voices of Chronic Pain Survey, 2006) this study furthers our understanding by hearing from individuals talk about these impacts in naturally occurring language. The inclusion of qualitative data such as, "I worry I won't be asked or included in the future if I am deemed too flaky to follow through" adds authenticity to the findings and a sense of pathos to the quantitative results. The

narrative extracts convey genuine testimonials and reinforces Nayar's (2010) claim that in digital environments, authenticity holds more solvency than credibility. Mitra (2004) argued that online interaction can be considered more meaningful and relevant; as a result, these finding impact readers on emotional levels by conveying realism and sincerity.

## **Limitations**

### **A. Discourse Analysis**

Although the interpretive repertoires may be helpful in understanding communication preferences among individuals with chronic pain, it is difficult to distinguish boundaries of the particular repertoires. While the case-to-case generalizability argued by Firestone (1993) provides the rationalization to generalize the particular findings to the general, the anti-realistic assumption of discourse analysis says the participants' accounts cannot be treated as true or false descriptions of reality. Rather, discourse analysis emphasizes certain versions of the world which are produced in discourse (Potter, 2004).

Further, the homogenous sample of the online writing workshop which consisted of predominantly Caucasian, educated, women who spoke English as their first language limits the application of this treatment modality. For this reason, caution must be used in extrapolating results as one cannot assume that this method is efficacious for males or cultural minorities. It is necessary to conduct similar writing workshops with larger and more diverse samples before this method can be deemed effective.

### **B. Computer Mediated Communication Reliance**

Since both methods involved the use of computed mediated communication, sample participants excludes those not inclined to use the internet or those who do not have access to it.

This limitation has specific implications for older persons who did not grow up in the digital culture and are less likely to adopt to internet communication practices.

The wording of survey questions inquiring about individuals' communication preferences with their health care provider was problematic in that individuals with chronic pain often have multiple doctors. Answers may vary widely depending on which provider they were thinking of. Future survey questions should be narrowed down to specify "primary health care provider" to avoid confusion.

### **C. Participant Cultural Trends in Chronic Pain Research**

There is a research bias when it comes to chronic pain in that an abundance of research on individuals with chronic pain is conducted by Scandinavian researchers, is published in the *Scandinavian Journal of Pain*, and Scandinavian women saturate the chronic pain research. The cultural considerations this reliance has may skew the research findings, especially when it comes to the discussion on credibility. In particular, Werner and Malterud's (2003) study provides a comprehensive look at the extent women struggle not only for their credibility, but also for the maintenance of self-esteem and dignity when consulting with a doctor, but their sample size is small, consisting of 10 Norwegian women. Werner, Isaksen and Malterud (2004) did a follow-up study to explore issues of shame in illness accounts from women with chronic pain, but they used the same 10 Norwegian women, so generalizability is limited. Moreover, these findings need to be examined in the light of the cultural consideration of Janteloven which prioritizes conformity and modesty as that may cloud disclosure practices.

Nguyen et al.'s (2013) study showed the extent of perceived negative stereotyping among chronic pain sufferers, using a large sample of over 12,000 women, aged 18-40, who live in Minneapolis/St. Paul, MN. Given that Minnesota is the state with the second highest rate of

Scandinavians, (Genetic Census of America, 2014) it is likely that their sample pool consists of Scandinavian women.

Icelandic researchers Skuladottir and Halldorsdotitir (2008) synthesized seven articles to develop a theory on women's efforts to retain self-control and avoid demoralization when interacting with health professionals regarding their chronic pain. Of the seven chronic pain articles they examined to inform their theory, five were conducted by and on Scandinavian researchers and participants. Johansson et al.'s (1996) study interviewed 20 Swedish women to better understand the asymmetrical power structure between providers and chronic pain patients.

Similarly, the writing workshop participants may add to this research bias as all participants were women and identified as White. An ethnic breakdown was not asked, but a majority of the participants resided in North Dakota and Minnesota where there is a high prevalence of Scandinavian descent.

The survey findings offset this research partiality by providing a more diverse population pool. In particular, the inclusion of male voices is a noteworthy contribution, with 22% of survey respondents being men. Further, survey respondents represent a larger age range, with 15% of the respondents' aged 25 years or younger and 12% of respondents aged 55 years or older. While 90% of respondents indicated they are White, the large geographic distribution precludes a Scandinavian bias. Although no respondents entered a Scandinavian locale, respondents could be of Scandinavian descent. While the survey data enlarges the perspective of individuals living with chronic pain, future research on chronic pain should consider selecting a more heterogeneous as well as larger participant pool.

## **Implications for Practice**

### **A. Need for Education**

The data indicate communicating about pain provides emotional support when the audience returns an empathetic response and the research highlights the heightened role family and friends play in offering emotional support in the lives of individuals with chronic pain. The large desire to receive emotional support from family and friends warrants further education and development aimed at the patients' support network to help individuals with chronic pain cope. Just as Ha and Longnecker (2010) noted that listening attentively, showing empathy, and using open-ended questions are strategies providers can use to demonstrate strong communication skills, so too can family and friends.

The workshop posts attending to visible indicators of pain show the varying degrees of awareness chronic pain sufferers have of the way their pain is manifested. The fact that indicators of pain are most often observed by children or coworkers, those that have close relationships to the pain sufferer, highlights the need for a support network to function as a mirror. By observing or imitating the pain behavior, they are acknowledging the person in pain; in a sense, they are validating the sufferer by communicating 'I see you and I see your pain'. Since pain sufferers may not be aware of their non-verbal communication, there is need to teach their support network the necessity to attend to non-verbal communication to better understand their pain language. As one participant continued, "My younger children don't have the capacity to understand yet. They will in time, and I only hope it teaches them some compassion from the experience of having a mom with pain issues."

Implications for practice include offering trainings and materials to chronic pain patients' family and support network. Similar to how the Health Resources and Services Administration

(n.d.) created web-based courses for providers to develop their cultural competency, new curriculum could be developed for family and friends of individuals with chronic pain to foster pain communication.

A recommendation stemming from the writing workshop is for the curriculum to include individuals with chronic pain to write out their pain plan. This agenda can help foster communication when the individual is consumed with pain and may not be able to communicate coherently. The list of directives can help family and friends care and support their loved one in ways that are desired by them. For example, workshop participants specifically wrote out their preferences for when they experience a pain flare-up; they indicated their desire to be touched or left alone and described specific ways in which they want help: “ask what tasks I want done—dishes washed, laundry folded and put away, let my dog out and feed all the critters.” Having a pain plan in place may empower individuals with chronic pain to receive their preferred support and can help cultivate respect and understanding of their pain. It may help them rest knowing specific instructions are at hand and their affairs will be in order. As one participant said, “It’s so lovely when the people who care about me are able to respond with grace and helpfulness without the fuss and fretting.”

### **B. Need for Inclusion of Family and Friends in Treatment Methods**

In particular, the web-based writing workshop curriculum for individuals with chronic pain may show promising results if the recruitment process was extended to allow family members and friends of individuals with chronic pain to participate. Then, the support network of the sufferers could hear how pain impacts the sufferers in their own words. Family and friends could contribute to the online workshop by posting supportive comments. By reading the posts from other sufferers, they may better understand the debilitating impacts and become aware of

unspoken needs of their loved one. Learning how other sufferers are affected by chronic pain may trigger open-ended questions to their loved one to see if they too feel this way or are impacted that way. Additionally, it may provide the platform to ask questions or voice concerns that may not be discussed in person but can be aired behind the veil of anonymity.

### **C. Need to Share Advice with Other Sufferers**

Further, the advice participants shared regarding insights pain has taught them surrounding respect, self-care and permission-giving can be useful to offer individuals newly diagnosed with a chronic pain condition. The sharing of lessons learned can help synthesize the experiential knowledge gained from living with chronic pain. Taken together, and if they were developed into a brochure or pamphlet, these affirmations attending to the value of pain and the need for self-care could serve as a helpful introduction to understanding the experience of living with chronic pain. These thoughtful compilations could help newly diagnosed individuals form realistic expectations and prepare for lifestyle adaptations.

Additionally, with the emphasis on using family and friends in a heightened supportive role, family and friends could also benefit from this advice to help encourage sufferers to care for themselves. Educating the support network of an individual with chronic pain can help foster patience, kindness, listening and emotional support. As one participant said, “I also have learned how important it is to educate those close to me on chronic pain and how it affects daily life. It is essential that those friends and family members closest to me not judge me or call me a whine or that it’s all in my head.”

As illustrated in the various interpretive repertoires, individuals with chronic pain take on different personas and reveal different communication depending on the audience. This finding is consistent with an analysis of health blogger features that shows females blog from a caregiver



perspective when writing about mental health and disease/disability experience but switch to writing from a patient or consumer perspective when the nature of the blog is on reproductive health or other subjects (Miller, Pole & Bateman, 2011). The ability to shift perspectives testifies for the need of anonymity so that women can choose which persona they want to write from and how much information they want to share. A recommendation for designing future computer mediated communication outlets is to provide users with screen names to protect identity and present them with a choice.

By providing a forum on which participants can share experiences, online support groups may play a role in reducing isolation and increasing connection with others (Ressler et al., 2012). Websites may be used to create a support network, and educate others, including health care providers, about their pain experiences (Cohen, 2005). As one tongue-tied participant wrote in response to another user helping her articulate her feelings, “I’ve never really pieced out my thoughts like this so finding the words is hard. It’s helpful to be able to talk with others who get it, or at least can complete my sentences.” The collective nature of sharing that happens among people sharing a common bond exemplifies Carey’s (1989) notion of ritualistic communication. Together, as shared collaborators, participants are creating meaning and making sense of their reality.

The potential for meaning-making among individuals who share a common experience such as living with chronic pain may hold promise for other individuals who share invisible, inaudible, immeasurable experiences. Specifically, these research findings and recommendations may hold merit for those that have suffered from sexual abuse or witnessed trauma. The use of computer mediated communication as a platform for support and the inclusion and heightened role of family and friends in the treatment method as well as the need for empathy and

opportunity to talk in their own words may find parallels among these other isolated and stigmatized populations.

### **Implications for Further Research**

This research has refined the scope of provider-patient communication preferences by providing patients' preferences for communicating with health care providers. While this patient perspective contributes to the literature, this research study highlights the relationship that pain communication is based on strategic disclosure. A study examining how individuals with chronic pain choose to disclose to others about their chronic pain, what are the responses, and how does it change relationships would be a suitable follow-up study. Participants in this study indicated that conversations were challenging to broker and this difficulty often led to undisclosed pain which distanced individuals from their friends. Future research on chronic pain disclosure practices could lessen feelings of isolation and marginalization.

Additionally, this study highlighted the heightened role family and friends play in offering emotional support to individuals with chronic pain. While training is needed to educate family and friends on ways to validate and empower their loved ones with chronic pain, it is unknown how to best deliver this training. Conducting research on family and friends through interviews or focus groups could elicit how they would like to receive training, preferred methods and curriculum that would inform training modules.

### **Conclusion**

Overall, discourse analysis provided the analytical starting point to understand the complex and intricate inter-relationships of language and social activity. Using the framework of the interpretive repertoires prevented an attempt to marshal out the variable and contradictory accounts of a single, inclusive story of what it's like to live with chronic pain. Instead, the focus

was to prioritize the thick descriptions of interpretations and their inferential implications as individuals try to make sense of the impacts and experience of chronic pain. The ability to study communication in naturally occurring situations which the online writing workshop presented is valuable for our understanding of how individuals with chronic pain organize their experience.

Ultimately, the mixed methods design which used the analysis of the posted responses from all writing workshop prompts to serve as a guide to further direct the line of inquiry helped reveal patient-provider communication preferences. While the literature review reviewed historic and current communication practices, the workshop findings point to the preferences. This study provided new understandings of the experience of living with chronic pain by offering new first-person accounts and prioritizing the patients' perspective, privileging sufferers' language, and honoring their lived experiences.

The writing workshop should be seen as a pilot study due to its small sample size and limited participant demographic information (education level, age, duration of pain). While initial findings hold merit to better understand communication preferences and prompts to help facilitate pain communication, a larger study sample is needed to confirm the value of this workshop as a viable method for therapy. Further, in subsequent replication studies, participants should be assessed at six and or 12 month follow-up intervals with several diverse outcome measures to determine the benefits of pain communication in a community of like-minded sufferers. A control group would lend validity to the study; however the present study was conducted as a means to gather preliminary research and to inform the survey tool. Conducting the online writing workshop within specific chronic pain populations may shed light on the utility of this treatment modality for certain types of chronic pain conditions, which could then increase generalizability.

While this is a cursory look at patient centered communication practices among individuals with chronic pain, it serves as an indication of my interest in better understanding patient needs and desires. As I continue to research the impacts of living with chronic pain my commitment to patient-centered health practices is secure. I look forward to becoming more involved in this trend.

## **APPENDICES**

## Appendix A: IRB-UND

U N I V E R S I T Y   O F      N O R T H   D A K O T A

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INSTITUTIONAL REVIEW BOARD  
c/o RESEARCH DEVELOPMENT AND COMPLIANCE  
DIVISION OF RESEARCH  
TWAMLEY HALL ROOM 106  
264 CENTENNIAL DRIVE STOP 7134  
GRAND FORKS ND 58202-7134  
(701) 777-4279  
FAX (701) 777-6708

December 30, 2013

Karin Becker  
Communication Program  
Stop 7169

Dear Ms. Becker:

We are pleased to inform you that your project titled, "Developing a Pain Vocabulary Online Workshop" (IRB-201312-225) has been reviewed and approved by the University of North Dakota Institutional Review Board (IRB). The expiration date of this approval is January 1, 2017.

As principal investigator for a study involving human participants, you assume certain responsibilities to the University of North Dakota and the UND IRB. Specifically, any adverse events or departures from the protocol that occur must be reported to the IRB immediately. It is your obligation to inform the IRB in writing if you would like to change aspects of your approved project, prior to implementing such changes.

When your research, including data analysis, is completed, you must submit a Research Project Termination form to the IRB office so your file can be closed. A Termination Form has been enclosed and is also available on the IRB website.

If you have any questions or concerns, please feel free to call me at (701) 777-4279 or e-mail [michelle.bowles@research.und.edu](mailto:michelle.bowles@research.und.edu).

Sincerely,



Michelle L. Bowles, M.P.A., CIP  
IRB Coordinator

MLB/jle

Enclosures

**PROTOCOL CHANGE FORM**  
**UNIVERSITY OF NORTH DAKOTA INSTITUTIONAL REVIEW BOARD**

Please complete this form and attach revised research documents for any proposed change to your protocol, consent forms, or any supportive materials (such as advertisements, questionnaires, surveys, etc.). All changes must be highlighted. Any proposed change in protocol affecting human participants must be reviewed and approved by the IRB prior to implementation, except where an immediate change is necessary to eliminate a hazard to the participant.

**Principal Investigator:** Karin Becker  
Telephone: 701 777-4499 E-mail Address: Karin.becker@email.und.edu  
Complete Mailing Address: 2515 Olive St. Grand Forks ND 58201  
School/College: University of North Dakota Department: Communication  
Project Title: Developing a Pain Vocabulary Online Workshop

**Proposal Number:** IRB-201312-225 **Approval Date:** Dec. 30, 2013

**THE CURRENT STATUS OF THE PROJECT IS (Check one)**

- Project currently in progress. Number of subjects enrolled is: 20  
 Project not yet started. No subjects enrolled.  
 Project closed to subject entry.

1. Briefly describe and explain the reason for the revision or amendment and the justification for the change. Include a copy of affected protocol pages and consent form with specific changes highlighted.

Due to a smaller than anticipated sample size I would like to offer a survey, similar to my pre-test survey, consisting of 26 questions, in an online format to try to increase responses. Specifically, I would like to post my survey on chronic pain devoted Facebook pages that are personally managed and not affiliated with an organization as well as through other social media websites such as Reddit and Twitter.

With this request, I am also switching advisors. Dr. Pasch is serving as my advisor and Dr. Rakow is no longer my advisor.

2. Does the change affect the study or subject participation (procedures, risks, costs, etc.)?  Yes  No

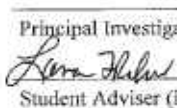

Please explain:

3. Does the change affect the consent document?  Yes  No

If yes, include the revised consent form(s) with the changes highlighted, and a clean copy of the revised consent form(s).

By signing below, you are verifying that the information provided in the Human Subjects Review Form and attached information is accurate and that the project will be completed as indicated.

Signatures:

Principal Investigator  Date: 2/16/15  
Student Adviser (if applicable)  Timothy J. Pasch, Ph.D. Date:

**Institutional Review Board**

Twamley Hall, Room 106  
264 Centennial Drive Stop 7134  
Grand Forks, ND 58202-7134  
Phone: 701.777.4279  
Fax: 701.777.6708

February 24, 2015

Principal Investigator:	Karin Becker
Project Title:	Developing a Pain Vocabulary Online Workshop
IRB Project Number:	IRB-201312-225
Project Review Level:	Exempt 2
Date of IRB Approval:	02/24/2015
Expiration Date of This Approval:	12/29/2016

The Protocol Change Form and all included documentation for the above-referenced project have been reviewed and approved via the procedures of the University of North Dakota Institutional Review Board.

You have approval for this project through the above-listed expiration date. When this research is completed, please submit a termination form to the IRB.

The forms to assist you in filing your project termination, adverse event/unanticipated problem, protocol change, etc. may be accessed on the IRB website: <http://und.edu/research/resources/human-subjects/>

Sincerely,



Michelle L. Bowles, M.P.A., CIP  
IRB Coordinator

MLB/jje

Enclosures

Cc: Lana Rakow, Ph.D.  
Timothy Pasch, Ph.D.



## Appendix B: IRB-Altru Health System



February 17, 2014

Karin Becker  
2515 Olive Street  
Grand Forks, ND 58201

RE: Developing a Chronic Pain Vocabulary Online Workshop. (ST-128)

Dear Ms. Becker,

We are pleased to inform you that your project has been reviewed and approved by Altru Health System Institutional Review Board (IRB). The expiration date of this approval is February 15, 2017. Your project cannot continue beyond this date without a protocol change.

As principal investigator for a study involving human participants, you assume certain responsibilities to Altru Health System and the Altru IRB. Specifically, any adverse events or protocol changes that occur must be reported to the IRB immediately. It is your obligation to inform the IRB in writing if you would like to change aspects of your approved project, prior to implementing such changes.

If your research, including data analysis, is completed before the expiration date, you must submit and complete a Research Project Termination Form so your file can be closed. All our forms can be found on the Altru Web Site: [www.altru.org](http://www.altru.org) (click on "about us", then on "research" and you will find "IRB" in the left column). Or on "AltruNet": (click on "policies and procedures" then "IRB"). Please send it to me at:

Marie-Laure Reese  
IRB, Office 101- Altru Psychiatry Center  
860 S. Columbia Road  
Grand Forks, ND 58201

Also along with the IRB approval, I included your Organizational Approval from Altru. In case of using the Medical Records, they required a copy of the signed IRB approval **two weeks prior** to the start of your research. Please send it to Jan Anderson (Medical Records Department, Altru Hospital, 2<sup>nd</sup> floor).

Sincerely,



Marie-Laure Reese  
IRB Coordinator

## Appendix C: Chronic Pain Writing Workshop Advertisement

**Have Chronic Pain?**

??\*?\*?!!!



Have trouble expressing your pain to your physician and loved ones?

Tired of getting sympathy or advice when you try to talk about your pain?

Participants are wanted for an online creative writing workshop.

Join a community of individuals with chronic pain and share experiences about how chronic pain impacts day-to-day living. Through weekly writing prompts, participants will:

- Explore and express pain
- Examine how pain impacts relationships
- Build language capacity to communicate it

This workshop will help you learn about and learn from your pain in a friendly, anonymous and secure online setting.

Workshop is **free**. Starts the week of **August 4 -- Sept14, 2014**.

Workshop is online so access it when convenient for you.

No writing experience is needed—come prepared to develop a pain vocabulary so that you can better understand, express, and advocate for your pain treatment.

For registration or for more information contact:

Karin Becker

Call or text: (701) 620-0189

Email: [Karin.becker@email.und.edu](mailto:Karin.becker@email.und.edu)

## Appendix D: Writing Workshop Welcome Page

### Chronic Pain Vocabulary

#### Developing a Pain Vocabulary by Writing our Pain

#### Story



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### Welcome

Welcome to the *Writing our Pain Story* workshop. This workshop aims to help individuals with chronic pain better observe our pain in hopes of better understanding it. Through a series of guided writing assignments, we will work on exploring and expressing our pain. Language is a powerful tool but is often inadequate when it comes to describing pain. Words cannot explain the intense, enduring and encompassing sensations of chronic pain, yet with or without words, the pain still exists. The focus of most conversations we have about pain is on getting rid of pain. Instead, we will work to observe pain, describe it and take stock of it so that we can better communicate it. This writing workshop will consist of weekly writing prompts that participants will need to complete and post. To build a collaborative online community I would like to encourage participants to comment on at least two other posts. These can be comments,

questions, or other feedback but will help us build a conversation. Participants should plan on spending 1-2 hours a week on assignments and commenting on others' posts.

**Class size:** This is a small workshop, consisting of approximately 9 people. I hope we get to know one another and learn from one another over the course of the workshop. It is okay to talk about this workshop or any posts with your friends and families; these writing prompts may trigger other conversations.

**Schedule:** Each Monday a new writing prompt will be posted. Please post your response by Thursday. Then, enjoy reading and commenting on each other's posts over the weekend. I will send out a courtesy email reminder each week:)

**No Judging/Grading:** Although we will be writing using creative writing techniques, there is no wrong way or wrong answer to these writing prompts. Since we live with chronic pain, we are the only ones who know what it is like. We hold all of the authority to write our story. This class hopes to empower you to use your expertise, insight and ultimately, your voice to better express and advocate for your needs.

The goal of this writing workshop is to understand, accept, express and learn from our pain. Building a better pain vocabulary may promote better self-management and enable us to become better advocates for pain treatment.

- **Understanding** refers to a patient having some basic knowledge about their pain condition and in particular, understanding how the mind and body interact to and respond to pain.

- **Accepting** refers to the patients' understanding and attitude towards the pain condition.
- **Expressing** refers to the ability to describe pain accurately, to convey it through language and disclose of it to others. Giving voice to our pain brings it out of the invisible, inaudible realm and may give it legitimacy and power. Disclosing of our pain to others helps us build a community of support and fosters inclusion and understanding.
- **Learning** from our pain allows us to be teachable, to be open to seeing pain as more than something to avoid but as a tool to better understand ourselves and our bodies.

Take some time with the writing. Find out when you write best. Enjoy reading what others have shared. To begin the workshop click on [Week 1- Taking Inventory](#)

## Appendix E: Writing Workshop Week 1– Taking Inventory

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Just like businesses need to account for and manage their inventory, we need to take stock of our pain. Sometimes, the nature of our pain is consistent like persistent lower back pain. However, sometimes our pain changes. A sudden ache in the wrist or soreness behind the knees pops up. Or, even though our pain is chronic, it's not every day. Sometimes a pain flare up lasts 2-3 days and then abates; other times it may last 3 weeks straight. The unpredictability of living with chronic pain makes it challenging to track our pain.



Taking stock of our pain from head to toe may help us see trends and patterns of our pain. For instance, I experienced constant jaw and pain in my left shoulder. One day, without doing anything different, I had pain in my right hamstring and limited movement in my right leg. It wasn't until weeks had passed and I went to a physical therapist that I was able to connect the pain all the way down and across my body and see that the two instances were inter-related. The pain in my left shoulder was causing poor posture, making the left shoulder droop. To compensate, my right hip went up, straining my right hamstring muscle.

The inter-relatedness of parts and pain helped me see my body holistically.

You may recall the old song “Dem Dry Bones” which says

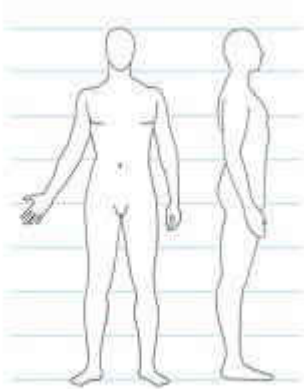
“The toe bone is connected to the foot bone,

The foot bone is connected to the heel bone,

The heel bone is connected to the ankle bone...and all the way up to the head.”

In the same way, examine your pain and trace your pain throughout the body. Look for patterns and linkages. Taking stock of our pain also helps document what aches currently and serves as a visual map to guide our focus.

Here is a picture of the body you can use:



**Writing Prompt:**

Starting with either the head or the foot, take inventory of your pain. You can write it as a verse to the Dry Bones song or an inventory list or a grocery list. While you take stock of the pain, write down how pain moves across, up or down your body. What is the direction it takes? Is the motion circular, linear, diagonal?

What constellation does it make? Note any patterns that may emerge.

Also note the duration of your pain. Does it last days or weeks? Does it come with rain (or other weather)? Is it worse in winter (or other season)?

Post your response in the “Reply” box below by Thursday and then click on the “Post Comment”

Please comment on other responses by simply hitting the “Reply” button under that post.



## Appendix F: Writing Workshop Week 2– Pain Impact Trails

We all suffer from pain but our experiences may differ. They are our own. While we may identify that pain is awful, something we wish we didn't experience, let's examine the ways in which it does impact us.

Others may get that we have pain, but they may not understand how pain colors our decisions, our actions, feelings, or commitments. The focus of this week's writing prompt is to examine the ways in which pain affects us and impacts our daily schedule. In other words, let's chart the way pain affects us on a daily level, from the time we wake up, throughout our day, to the time we sleep. We will compare how we act or perform duties when we feel well versus how we act when we have a flare up.

This may be a different way of thinking of pain but it may reveal some patterns or trends. In this way, we will look at both the internal and external manifestations of our pain.



How does pain impact us? How does pain appear?

For example, when I come home from work and see the house a mess I normally start to try to organize the mess. First, I will start with washing the dishes in the sink. When I have a pain flare up, I don't even see the dishes in the sink.

Another example is a friend who wore her hair in a braid when she was in pain to keep her hair out of her face. She didn't even know she did this until her housemate realized this trend. Her housemate better knew how to respond to her when he saw that her hair was braided.

**Writing Prompt:** Take some time and chart how pain impacts your day-to-day living experiences. Account for some of the ways you negotiate around pain in your daily living. How does pain impact your ability to do housework? Errands? Chores? Work? Travel? What have you had to give up or change because of the chronic pain?

Action/Event	Feeling Well (normal)	Pain Flare-up
Getting to work	Listen to NPR in car	Speed and curse about traffic moving slowly
At work	Talk with colleagues	Retreat inwardly; avoid others
Afternoon	Go to gym	Go to bed
Dinner	Enjoy cooking	Eat Ramen noodles

These adaptations may help signal to loved ones that we are in pain. We may not even be aware of it or communicate it, but by knowing how our body and behavior changes when we have a pain flare up we can help those around us better respond to us.

## Appendix G: Writing Workshop Week 3– Credo

More than anything this workshop is designed to give credence to the lived experiences we have as individuals with chronic pain. It is so hard to translate a subjective and personal sensation such as pain into words. Although health care providers may know how to diagnose and treat pain, they do not understand the day-to-day experience of living with chronic pain.

Our cultural values tell us to be stoic and strong, and not to talk about or show weakness. Our societal values tell us to be healthy and look youthful. To disclose of a pain or a disabling condition can cast us in a negative light and stigmatize us as different. We may be viewed as complainers and whiners. Professionally, there can be severe repercussions to disclose of our chronic pain condition. All of these conventional values discourage us from talking about a huge part of our identity and our life experience.

**Writing Prompt:** I invite you to write a credo, a statement of personal beliefs, that you know to be true regarding your experience with chronic pain or a chronic pain condition. In this way, we are subject matter experts. Based on our expertise, share with others one insight or lesson learned. Imagine your audience as someone who may recently be diagnosed or have questions about your condition but are afraid to ask because they don't want to pry. What advice can you offer them? What tips have you learned along the way?

The contribution can be in the form of statements or an essay but it will emphasize your voice, your experience. Write it using language that is yours and reflects your personal story. Stemming from your experiences with chronic pain, what do you know to be true?

For reference, National Public Radio invited listeners to write their own credo in the form of "This I Believe" where listeners wrote about personal values and beliefs and read them in their own voice in under three minutes. The credos are categorized by themes and love, self-determination and self-knowledge have the largest contributions. You can hear them at: <http://thisibelieve.org/search/>

## Appendix H: Writing Workshop Week 4– Pain Plan

This week we will try to share our experience of living with chronic pain to a loved one. The intended audience is your care taker--your spouse, child, aunt, parent, roommate or neighbor. The goal is to provide them with useful knowledge of what you would like them to do, to know, or to take care of when you are having "a bad pain day," or a "flare up".

Similar to a birthing plan where expecting mothers outline their labor plans and pack their bags carefully, what is your pain plan? Although we know birthing plans rarely happen as planned, the idea of a plan can give assurance to the expecting mother and a feeling of preparedness in this time of uncertainty. Most importantly, a plan can allow others to feel included and informed.

In this way, what is your ideal pain plan? What would be in your pain bag? Lip balm, cold wash clothes, hot towels, applied where? Neck massage or foot massage? With lotion or oil?

When you are gripped by pain, what type and what amount of care do you want? What kinds of food or drink do you prefer? Do you like music or silence? Do you like natural light or darkness? Is it helpful for you to have company or do you prefer to be left alone? What medications do you take and where do you keep them? How much is a dose and how often do you take it? What cannot be forgotten--child care, pet care, plant care; when is garbage day?

**Writing Prompt:** Write out specific pain plans to share with your spouse, family members, or care taker.

## Appendix I: Writing Workshop Week 5– Mice and Metaphors

### *The Mouse in the Room*

Sometimes, to get at abstract sensations such as pain, we need abstract language. Metaphors and similes work by drawing comparisons between things that are unexpected, unlikely or unique.

For example, a common simile is "love is like a flower" and a metaphor is "love is a thorny rose".

The phrase of "the elephant in the room" refers to an escalating conflict that is readily apparent yet no one wants to address it. The elephant is a metaphor for a problem that is obvious and undeniable, yet because of or despite its improbability of it being stuffed in a room, people hate discuss it. This expression gives testament to the power of metaphor and its ability to enter into a culture's expressions. Metaphors are powerful tools which can create mental and emotional associations. Over time, metaphors can be used as shortcuts to speech and they are chosen for their ability to convey sentiments in quick and easy language.



Contrary to the elephant in the room, chronic pain can be expressed metaphorically as the mouse in the room. Pain is not visibly identifiable; its presence is small and unseen. Unlike the elephant

which by its sheer heft and weight takes center stage, a mouse is silent, small and unobtrusive. In order to prove that a mouse exists, one has to catch it. Evidence is shown when the mouse is trapped.

Similarly, chronic pain has to be "trapped" to be verified. Only then can it be observed, measured and quantified. Yet we know that mice are elusive; they resist the bait to be captured and sometimes, they take the cheese yet escape the traps. This elusiveness is the nature of pain. The only confirmation that we have mice is the telltale sign of their excrement. These droppings visually convey that a mouse exists, but locating it or diagnosing how it got in the house is not revealed.

So too is it with pain where the individual has the symptoms of pain but may not know what its origin is or how it started.



Additionally, this mouse metaphor works on social levels. Mice are considered rodents, potential carriers of infectious disease and signs of poor housekeeping. Likewise, chronic pain may be associated with an underlying chronic disease and may be part of a larger picture of poor dietary or lifestyle choices. However, this is not always the case. Chronic pain may be the result of injury, trauma, genetic disorders, congenital conditions or mental health illness or none of the

above. What is consistent is that to the individual, chronic pain is viewed as a pest and socially, it is something others do not want. It poisons hospitality and can make guests feel uncomfortable.

Whether we are talking of elephants or mice, the power of metaphor is seen. The utility and succinctness of metaphor and similes make them strong linguistic tools.

**Writing Prompt:** Try writing a metaphor and simile to describe your pain. You can use simile where you make a comparison using the words "like" or "as". Have fun thinking of unusual associations. Use descriptive language to explain pain.

Pain is a \_\_\_\_\_

Pain is like a \_\_\_\_\_

My pain feels like being \_\_\_\_\_ (hit/ struck/ poked....) by a \_\_\_\_\_

If pain were a color it would be \_\_\_\_\_ because...

The sound of pain is \_\_\_\_\_ like a \_\_\_\_\_

Try a character sketch. Cast your pain as a monster or super hero. Describe this character--dress it.

Remember, these are not graded assignments. There is no judgment.



## Appendix J: Writing Workshop Week 6– Thank You

First, I want to thank all of you for your participation and willingness to share. I am really pleased with the exchanges and posts and have learned a lot. If you are interested, I would like to share my findings with you when I have finished looking at the themes from both workshops. Please let me know of your interest and I can email you.

**Other thoughts:** This website will be active until September 20. Would you like access to it longer than that to review comments?

Just as we started with a survey, we will end with a final survey. Please complete a post-workshop survey sometime this week. Questions are similar to the pre-workshop survey and you will need to enter the 7-digit pin you created. You can click on the link and it will take you directly to the survey.

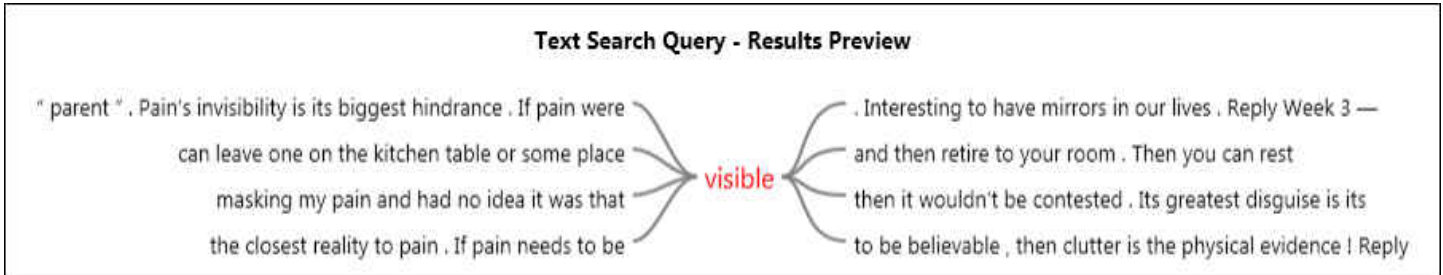
[https://und.qualtrics.com/SE/?SID=SV\\_9Tamzq59ltpXSYd](https://und.qualtrics.com/SE/?SID=SV_9Tamzq59ltpXSYd)



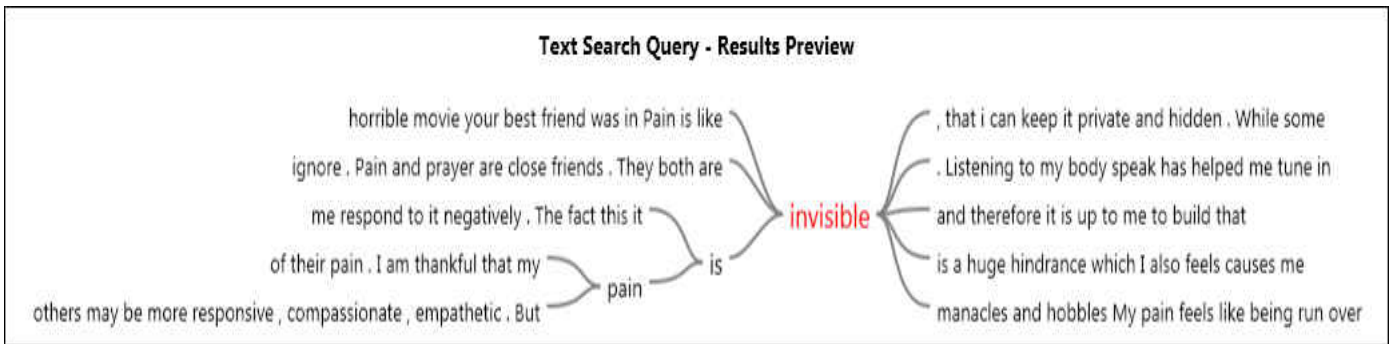
Lastly, our writing. The final week of the workshop will conclude with a thank you letter to an unlikely recipient: pain. This thank you letter is addressed to pain and is a way for you to think of things that pain has afforded you or allowed you to do or gotten you out of things. For example, pain has given me the excuse to get out of many dull and dry department meetings. It has allowed me to stay in bed on cold, dark, wintry mornings when the flannel sheets are warm and welcoming.

## Appendix K: NVIVO Word Clouds

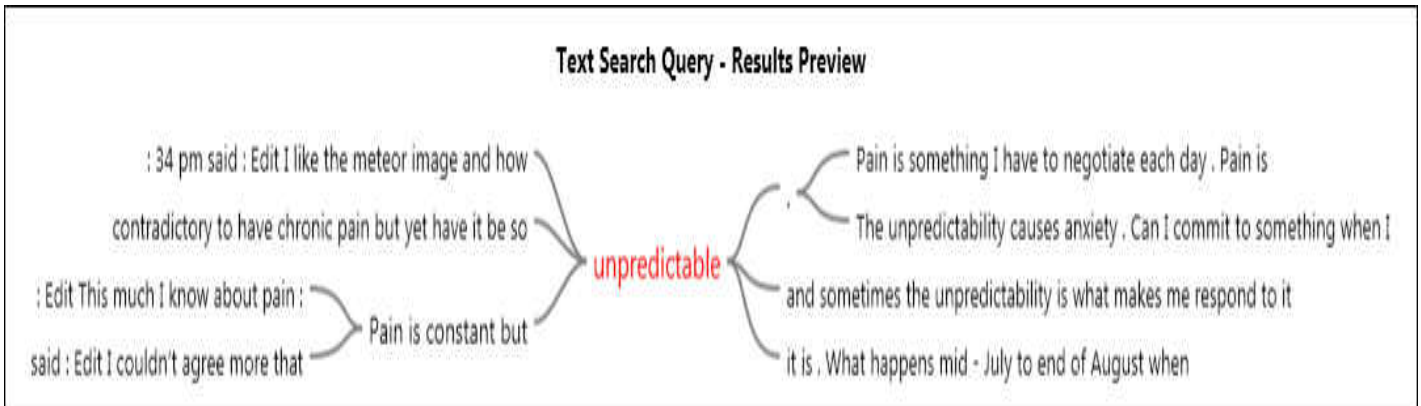
### Pain as discredited self: Physical evidence



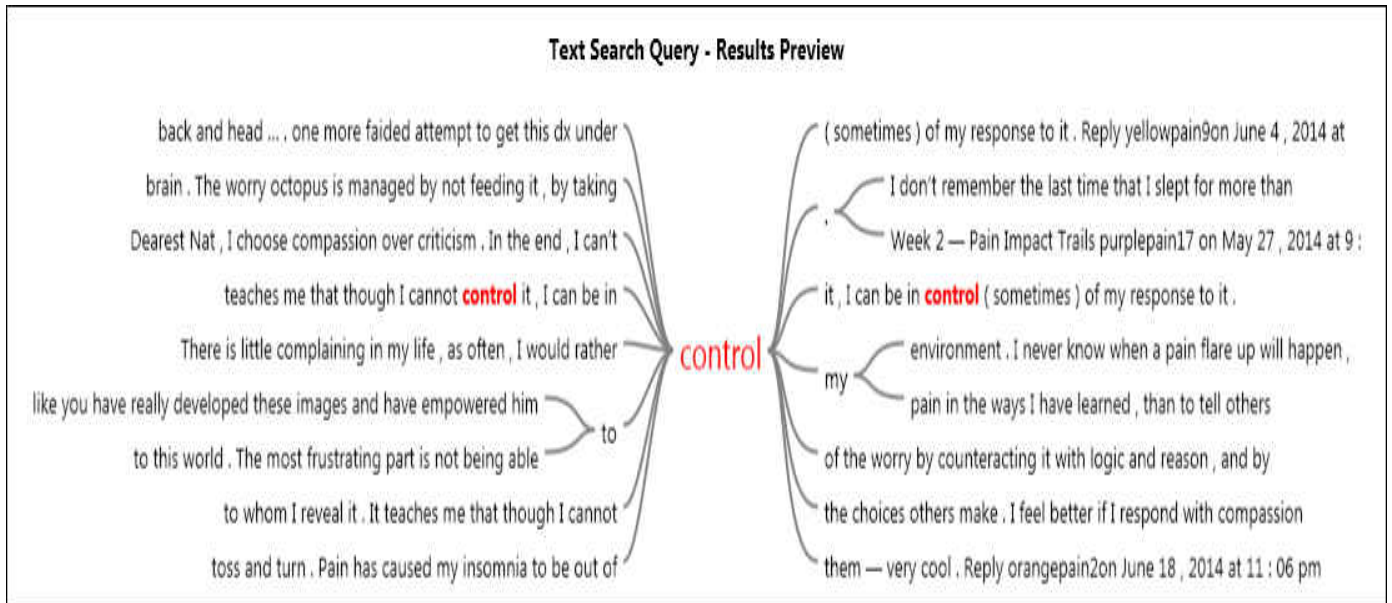
### Pain as discredited self : Invalidation



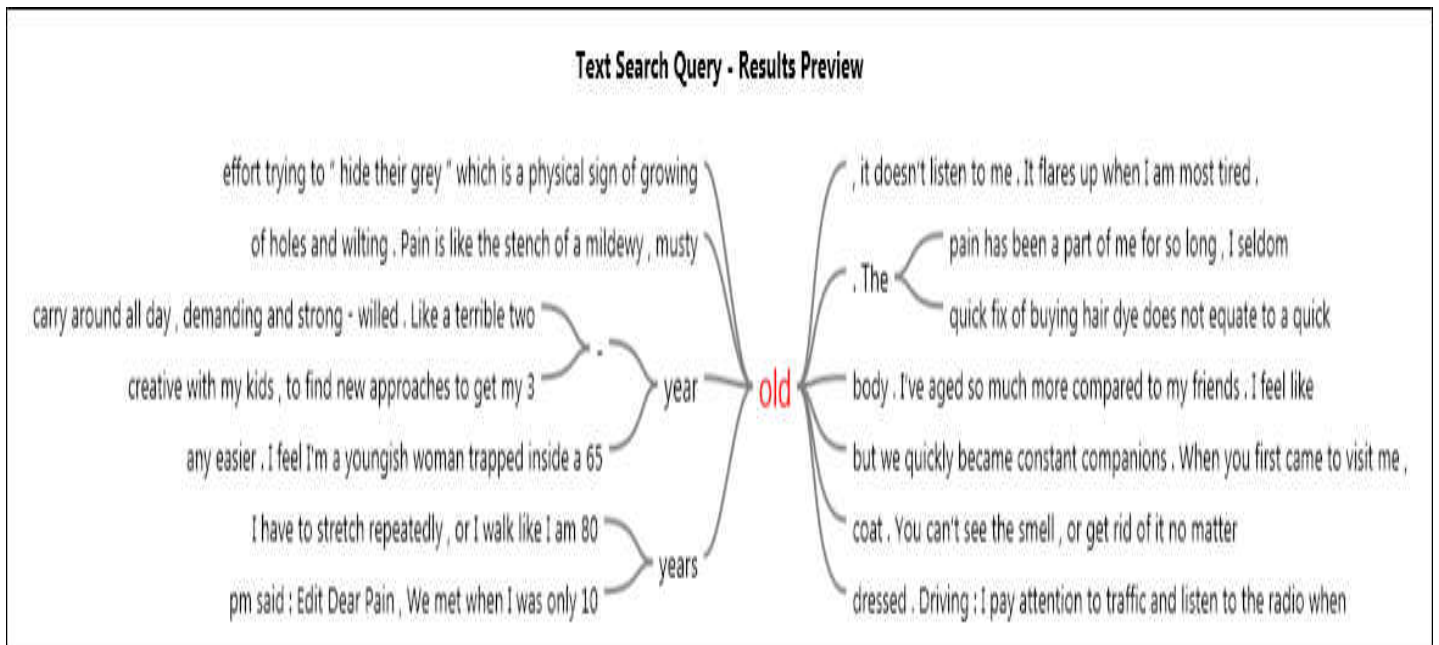
### Pain as fragmented self: Discontinuity



## Pain as framented self: Lack of control



## Pain as multi-faceted phenomena: Mental: Aging Impacts



## **Appendix L: Survey Tool**

### **Chronic Pain Communication Practices Survey**

This survey is designed to better understand the ways individuals with chronic pain talk about their pain. Specifically, I am interested in learning to whom and in what ways you talk about pain. As a chronic pain sufferer, I understand the difficulty in trying to convey an abstract sensation like pain to others. However, I am investigating if there is any therapeutic value in talking about pain.

#### **Informed Consent Form**

The information collected by this survey will provide the means to better understand pain sufferers' description of pain, preferences in talking about pain and will be used for educational research purposes.

The results of this survey are anonymous and will be kept confidential. The survey consists of 25 questions and should take about 5-8 minutes to complete.

This survey is voluntary and you may stop taking the survey at any time.

If you have any questions or comments about this study, I would be very interested in hearing from you. Please do not hesitate to email me at [karin.becker@email.und.edu](mailto:karin.becker@email.und.edu)

By clicking on the "Yes-participate" button below, you agree that you are consenting to participate in this study. If you do not want to take part in the study, click on the "No-refuse" button below.

Thank you!

Karin Becker,

PhD Candidate, University of North Dakota

Q1 I agree to participate in this study

Yes-participate (1)

No-refuse (2)

If No-refuse Is Selected, Then Skip To End of Survey

Q2 . Do you experience chronic pain?

Yes (1)

No (2)

If no Is Selected, Then Skip To End of Survey

Q3 Have you been diagnosed with a chronic pain condition?

Yes (1)

No (2)

Q4 My pain impacts me: (Choose all that apply)

Emotionally (1)

Physically (2)

Mentally (3)

Financially (4)

Spiritually (5)

Other (6) \_\_\_\_\_

Q5 I have had to miss work or cancel a social outing due to chronic pain:

- Constantly (1)
- Frequently (2)
- Occasionally (3)
- Rarely (4)
- Never (5)
- Other (6) \_\_\_\_\_

Q6 My pain disrupts my day-to-day living:

- Constantly (1)
- Frequently (2)
- Occasionally (3)
- Rarely (4)
- Never (5)
- Other (6) \_\_\_\_\_

Q7 Outside of your health care provider, with whom do you talk about your chronic pain?

(Choose all that apply)

- Spouse (1)
- Children (2)
- Other family members (3)
- Friends (4)
- Co-workers (5)
- I don't talk (6)
- Other (7) \_\_\_\_\_

Q8 In everyday conversations, how often do you talk about your pain to friends and family?

- Constantly (1)
- Frequently (2)
- Occasionally (3)
- Rarely (4)
- Never (5)
- Other (6) \_\_\_\_\_



Q9 I am able to adequately describe my pain:

- Strongly Agree (31)
- Agree (32)
- Neither Agree nor Disagree (33)
- Disagree (34)
- Strongly Disagree (35)
- Other (36) \_\_\_\_\_

Q10 I feel that my health care provider understands my pain when I describe it:

- Strongly Agree (16)
- Agree (17)
- Neither Agree nor Disagree (18)
- Disagree (19)
- Strongly Disagree (20)
- Other (21) \_\_\_\_\_

Q11 I think my health care provider understands how pain impacts my life:

- Strongly Agree (11)
- Agree (12)
- Neither Agree nor Disagree (13)
- Disagree (14)
- Strongly Disagree (15)
- Other (16) \_\_\_\_\_

Q12 I feel emotionally supported when I talk about my pain:

- Strongly Agree (16)
- Agree (17)
- Neither Agree nor Disagree (18)
- Disagree (19)
- Strongly Disagree (20)
- Other (21) \_\_\_\_\_

Q13 I feel talking about my pain is beneficial to me:

- Strongly Agree (11)
- Agree (12)
- Neither Agree nor Disagree (13)
- Disagree (14)
- Strongly Disagree (15)
- Other (16) \_\_\_\_\_

Q14 I feel others are interested in learning about my chronic pain experience:

- Strongly Agree (11)
- Agree (12)
- Neither Agree nor Disagree (13)
- Disagree (14)
- Strongly Disagree (15)
- Other (16) \_\_\_\_\_

Q15 I feel supported and understood when I talk about my pain with my health care provider:

- Strongly Agree (11)
- Agree (12)
- Neither Agree nor Disagree (13)
- Disagree (14)
- Strongly Disagree (15)
- Other (16) \_\_\_\_\_

Q16 I feel supported and understood when I talk about my pain with my friends & family:

- Strongly Agree (11)
- Agree (12)
- Neither Agree nor Disagree (13)
- Disagree (14)
- Strongly Disagree (15)
- Other (16) \_\_\_\_\_

Q17 On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance, please rank the following items you would like your health care provider to offer you:

	Least important (1)	Click to write Scale point 2 (2)	Click to write Scale point 3 (3)	Click to write Scale point 4 (4)	Most important (5)
Empathy regarding the debilitating impacts of chronic pain (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information about my chronic pain condition (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information about my treatment plan (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Opportunity for me to talk about my pain, in my own words (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support for my emotional well-being (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q18 On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance, please rank the following items you would like your family and friends to offer you:

	Least important (1)	Click to write Scale point 2 (2)	Click to write Scale point 3 (3)	Click to write Scale point 4 (4)	Most important (5)
Empathy regarding the debilitating impacts of chronic pain (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information about my chronic pain condition (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information about my treatment plan (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Opportunity for me to talk about my pain, in my own words (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support for my emotional well-being (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q19 To better understand my chronic pain, I wish my health care provider would ask me more about how chronic pain: (choose all that apply)

- impacts my daily activities (1)
- impacts my social and family relationships (2)
- impacts my work responsibilities (3)
- impacts my self-image and self-esteem (4)
- impacts my goals and dreams (5)
- nothing, I don't want to talk to them about any of these (6)
- Other (7) \_\_\_\_\_

Q20 To better understand my chronic pain, I wish my family and friends would ask me more about: (choose all that apply)

- impacts my daily activities (1)
- impacts my social and family relationships (2)
- impacts my work responsibilities (3)
- impacts my self-image and self-esteem (4)
- impacts my goals and dreams (5)
- nothing, I don't want to talk to them about any of these (6)
- Other (7) \_\_\_\_\_

Q21. Please indicate your gender:

- Male (1)
- Female (2)

Q22. Please indicate your age:

- less than 25 years (1)
- 25-34 years (2)
- 35-44 years (3)
- 45-54 years (4)
- 55-64 years (5)
- 65 years or older (6)

Q23. Please indicate the race that best describes you:

- White (1)
- Black or African American (2)
- Asian (3)
- American Indian (4)
- Other (5)
- Prefer not to answer (6)

Q24. Please indicate the highest level of education that you have achieved:

- High school diploma or GED (1)
- Some college (2)
- Associates degree (3)
- Bachelor's degree (4)
- Masters, Doctorate or Professional degree (5)
- Other (6)

25 Please indicate your insurance status: (Choose all that apply)

- Insurance through employer (9)
- Private insurance (10)
- Medicaid (11)
- Medicare (12)
- Tribal insurance (13)
- Indian Health Services (14)
- Veteran's Health Care Benefits (15)
- Uninsured/ underinsured (16)
- Other (17)

26 Please enter your city and state/country

Thank you for your participation!

## Appendix M: SPSS Descriptive Statistics

### Survey Response Descriptive Statistics

#### Group Statistics

Questions 2-4	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
2. Do you experience chronic pain?	Male	35	1.00	.000 <sup>a</sup>	.000
	Female	127	1.00	.000 <sup>a</sup>	.000
3. Have you been diagnosed with a chronic pain condition?	Male	34	1.18	.387	.066
	Female	125	1.10	.306	.027
4. My pain impacts me: (Choose all that apply)- Emotionally	Male	31	1.00	.000 <sup>a</sup>	.000
	Female	119	1.00	.000 <sup>a</sup>	.000
My pain impacts me: (Choose all that apply)- Physically	Male	35	1.00	.000 <sup>a</sup>	.000
	Female	125	1.00	.000 <sup>a</sup>	.000
My pain impacts me: (Choose all that apply)- Mentally	Male	30	1.00	.000 <sup>a</sup>	.000
	Female	119	1.00	.000 <sup>a</sup>	.000
My pain impacts me: (Choose all that apply)- Financially	Male	24	1.00	.000 <sup>a</sup>	.000
	Female	96	1.00	.000 <sup>a</sup>	.000

My pain impacts me: Male	11	1.00	.000 <sup>a</sup>	.000
(Choose all that apply)- Female	36	1.00	.000 <sup>a</sup>	.000
Spiritually				
My pain impacts me: Male	3	1.00	.000 <sup>a</sup>	.000
(Choose all that apply)- Female	15	1.00	.000 <sup>a</sup>	.000
Other				

a. t cannot be computed because the standard deviations of both groups are 0.

### Group Statistics

Q 5.	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
I have had to miss work or cancel a social outing due to chronic pain:- Constantly	Male	16	1.00	.000 <sup>a</sup>	.000
	Female	31	1.00	.000 <sup>a</sup>	.000
I have had to miss work or cancel a social outing due to chronic pain:- Frequently	Male	13	1.00	.000 <sup>a</sup>	.000
	Female	48	1.00	.000 <sup>a</sup>	.000
	Male	5	1.00	.000 <sup>a</sup>	.000

I have had to miss work Female or cancel a social outing due to chronic pain:- Occasionally	40	1.00	.000 <sup>a</sup>	.000
I have had to miss work Male or cancel a social outing Female due to chronic pain:- Rarely	1 9	1.00 1.00	. .000	. .000
I have had to miss work Male or cancel a social outing Female due to chronic pain:- Never	1 1	1.00 1.00	. .	. .
I have had to miss work Male or cancel a social outing Female due to chronic pain:- Other	2 3	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000

a. t cannot be computed because the standard deviations of both groups are 0.

### Group Statistics

Q. 6	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
	Male	26	1.00	.000 <sup>a</sup>	.000

My pain disrupts my day-to-day living:- Constantly	Female	62	1.00	.000 <sup>a</sup>	.000
My pain disrupts my day-to-day living:- Frequently	Male Female	6 46	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
My pain disrupts my day-to-day living:- Occasionally	Male Female	3 23	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
My pain disrupts my day-to-day living:- Rarely	Male Female	0 <sup>b</sup> 2	. 1.00	. .000	. .000
My pain disrupts my day-to-day living:- Never	Male Female	0 <sup>b</sup> 0 <sup>b</sup>	. .	. .	. .
My pain disrupts my day-to-day living:- Other	Male Female	0 <sup>b</sup> 1	. 1.00	. .	. .

a. t cannot be computed because the standard deviations of both groups are 0.

b. t cannot be computed because at least one of the groups is empty.



**Group Statistics**

Q 7	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
Outside of your health care provider, with whom do you talk about your chronic pain? (Choose all...-Spouse	Male	20	1.00	.000 <sup>a</sup>	.000
	Female	89	1.00	.000 <sup>a</sup>	.000
Outside of your health care provider, with whom do you talk about your chronic pain? (Choose all...-Children	Male	4	1.00	.000 <sup>a</sup>	.000
	Female	23	1.00	.000 <sup>a</sup>	.000
Outside of your health care provider, with whom do you talk about your chronic pain? (Choose all...-Other family members	Male	20	1.00	.000 <sup>a</sup>	.000
	Female	65	1.00	.000 <sup>a</sup>	.000
	Male	20	1.00	.000 <sup>a</sup>	.000

Outside of your health care provider, with whom do you talk about your chronic pain? (Choose all...-Friends	Female	73	1.00	.000 <sup>a</sup>	.000
Outside of your health care provider, with whom do you talk about your chronic pain? (Choose all...-Co-workers	Male Female	5 24	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
Outside of your health care provider, with whom do you talk about your chronic pain? (Choose all...-I don't talk	Male Female	5 12	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
Outside of your health care provider, with whom do you talk about your chronic pain? (Choose all...-Other	Male Female	3 20	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000

a. t cannot be computed because the standard deviations of both groups are 0.

### Group Statistics

Q8	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
. In everyday conversations, how often do you talk about your pain to friends and family? -Constantly	Male	0 <sup>a</sup>	.	.	.
	Female	4	1.00	.000	.000
In everyday conversations, how often do you talk about your pain to friends and family? -Frequently	Male	6	1.00	.000 <sup>b</sup>	.000
	Female	22	1.00	.000 <sup>b</sup>	.000
In everyday conversations, how often do you talk about your pain to friends and family? -Occasionally	Male	12	1.00	.000 <sup>b</sup>	.000
	Female	59	1.00	.000 <sup>b</sup>	.000
	Male	12	1.00	.000 <sup>b</sup>	.000

In everyday conversations, how often do you talk about your pain to friends and family?-Rarely	Female	41	1.00	.000 <sup>b</sup>	.000
In everyday conversations, how often do you talk about your pain to friends and family?-Never	Male	6	1.00	.000	.000
In everyday conversations, how often do you talk about your pain to friends and family?-Never	Female	1	1.00	.	.
In everyday conversations, how often do you talk about your pain to friends and family?-Other	Male	1	1.00	.	.
In everyday conversations, how often do you talk about your pain to friends and family?-Other	Female	2	1.00	.000	.000

a. t cannot be computed because at least one of the groups is empty.

### Group Statistics

Q. 9	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
	Male	7	1.00	.000 <sup>a</sup>	.000

I am able to adequately describe my pain:- Strongly Agree	Female	18	1.00	.000 <sup>a</sup>	.000
I am able to adequately describe my pain:- Agree	Male Female	12 48	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
I am able to adequately describe my pain:- Neither Agree nor Disagree	Male Female	7 19	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
I am able to adequately describe my pain:- Disagree	Male Female	7 38	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
I am able to adequately describe my pain:- Strongly Disagree	Male Female	2 5	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
I am able to adequately describe my pain:-Other	Male Female	0 <sup>b</sup> 1	. 1.00	. .	. .

a. t cannot be computed because the standard deviations of both groups are 0.

b. t cannot be computed because at least one of the groups is empty.

**Group Statistics**

Q. 10	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
I think my health care provider understands how pain impacts my life:-Strongly Agree	Male	4	1.00	.000 <sup>a</sup>	.000
	Female	12	1.00	.000 <sup>a</sup>	.000
I think my health care provider understands how pain impacts my life:-Agree	Male	8	1.00	.000 <sup>a</sup>	.000
	Female	47	1.00	.000 <sup>a</sup>	.000
I think my health care provider understands how pain impacts my life:-Neither Agree nor Disagree	Male	4	1.00	.000 <sup>a</sup>	.000
	Female	24	1.00	.000 <sup>a</sup>	.000
I think my health care provider understands how pain impacts my life:-Disagree	Male	11	1.00	.000 <sup>a</sup>	.000
	Female	32	1.00	.000 <sup>a</sup>	.000
	Male	8	1.00	.000 <sup>a</sup>	.000

I think my health care provider understands how pain impacts my life:-Strongly Disagree	Female	11	1.00	.000 <sup>a</sup>	.000
I think my health care provider understands how pain impacts my life:-Other	Male	0 <sup>b</sup>	.	.	.
	Female	5	1.00	.000	.000

a. t cannot be computed because the standard deviations of both groups are 0.

b. t cannot be computed because at least one of the groups is empty.

### Group Statistics

Q 11.	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
I think my health care provider understands how pain impacts my life:-Strongly Agree	Male	4	1.00	.000 <sup>a</sup>	.000
	Female	12	1.00	.000 <sup>a</sup>	.000
	Male	8	1.00	.000 <sup>a</sup>	.000

I think my health care provider understands how pain impacts my life:-Agree	Female	47	1.00	.000 <sup>a</sup>	.000
I think my health care provider understands how pain impacts my life:-Neither Agree nor Disagree	Male Female	4 24	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
I think my health care provider understands how pain impacts my life:-Disagree	Male Female	11 32	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
I think my health care provider understands how pain impacts my life:-Strongly Disagree	Male Female	8 11	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
I think my health care provider understands how pain impacts my life:-Other	Male Female	0 <sup>b</sup> 5	. 1.00	. .000	. .000

a. t cannot be computed because the standard deviations of both groups are 0.

b. t cannot be computed because at least one of the groups is empty.



### Group Statistics

Q12.	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
I feel emotionally supported when I talk about my pain:- Strongly Agree	Male	0 <sup>a</sup>	.	.	.
	Female	8	1.00	.000	.000
I feel emotionally supported when I talk about my pain:-Agree	Male	10	1.00	.000 <sup>b</sup>	.000
	Female	41	1.00	.000 <sup>b</sup>	.000
I feel emotionally supported when I talk about my pain:-Neither Agree nor Disagree	Male	11	1.00	.000 <sup>b</sup>	.000
	Female	37	1.00	.000 <sup>b</sup>	.000
I feel emotionally supported when I talk about my pain:- Disagree	Male	9	1.00	.000 <sup>b</sup>	.000
	Female	35	1.00	.000 <sup>b</sup>	.000
	Male	6	1.00	.000 <sup>b</sup>	.000

I feel emotionally supported when I talk about my pain:- Strongly Disagree	Female	9	1.00	.000 <sup>b</sup>	.000
I feel emotionally supported when I talk about my pain:-Other	Male	1	1.00	.	.
	Female	5	1.00	.000	.000

a. t cannot be computed because at least one of the groups is empty.

b. t cannot be computed because the standard deviations of both groups are 0.

### Group Statistics

Q 13.	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
I feel talking about my pain is beneficial to me:-Strongly Agree	Male	1	1.00	.	.
	Female	16	1.00	.000	.000
I feel talking about my pain is beneficial to me:-Agree	Male	9	1.00	.000 <sup>a</sup>	.000
	Female	52	1.00	.000 <sup>a</sup>	.000
I feel talking about my pain is beneficial to me:-Neither Agree nor Disagree	Male	18	1.00	.000 <sup>a</sup>	.000
	Female	33	1.00	.000 <sup>a</sup>	.000

I feel talking about my pain is beneficial to me:-Disagree	Male	6	1.00	.000 <sup>a</sup>	.000
	Female	21	1.00	.000 <sup>a</sup>	.000
I feel talking about my pain is beneficial to me:-Strongly Disagree	Male	5	1.00	.000 <sup>a</sup>	.000
	Female	2	1.00	.000 <sup>a</sup>	.000
I feel talking about my pain is beneficial to me:-Other	Male	1	1.00	.	.
	Female	2	1.00	.000	.000

a. t cannot be computed because the standard deviations of both groups are 0.

### Group Statistics

Q 14.	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
I feel others are interested in learning about my chronic pain experience: Strongly Agree	Male	1	1.00	.	.
	Female	4	1.00	.000	.000
	Male	5	1.00	.000 <sup>a</sup>	.000

I feel others are interested in learning about my chronic pain experience: the Agree	Female	10	1.00	.000 <sup>a</sup>	.000
I feel others are interested in learning about my chronic pain experience:	Male	4	1.00	.000 <sup>a</sup>	.000
Neither Agree nor Disagree	Female	26	1.00	.000 <sup>a</sup>	.000
I feel others are interested in learning about my chronic pain experience:	Male	16	1.00	.000 <sup>a</sup>	.000
Disagree	Female	47	1.00	.000 <sup>a</sup>	.000
I feel others are interested in learning about my chronic pain experience:	Male	9	1.00	.000 <sup>a</sup>	.000
Strongly Disagree	Female	38	1.00	.000 <sup>a</sup>	.000
	Male	3	1.00	.000 <sup>a</sup>	.000

I feel others are interested in learning about my chronic pain experience:...-Other	Female	4	1.00	.000 <sup>a</sup>	.000
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a. t cannot be computed because the standard deviations of both groups are 0.

### Group Statistics

Q 15	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
I feel supported and understood when I talk about my pain with my health care provider:- Strongly Agree	Male	0 <sup>a</sup>	.	.	.
	Female	10	1.00	.000	.000
I feel supported and understood when I talk about my pain with my health care provider:- Agree	Male	12	1.00	.000 <sup>b</sup>	.000
	Female	42	1.00	.000 <sup>b</sup>	.000
	Male	9	1.00	.000 <sup>b</sup>	.000

I feel supported and understood when I talk about my pain with my health care provider:- Neither Agree nor Disagree	Female	37	1.00	.000 <sup>b</sup>	.000
I feel supported and understood when I talk about my pain with my health care provider:- Disagree	Male	11	1.00	.000 <sup>b</sup>	.000
I feel supported and understood when I talk about my pain with my health care provider:- Disagree	Female	29	1.00	.000 <sup>b</sup>	.000
I feel supported and understood when I talk about my pain with my health care provider:- Strongly Disagree	Male	4	1.00	.000 <sup>b</sup>	.000
I feel supported and understood when I talk about my pain with my health care provider:- Strongly Disagree	Female	9	1.00	.000 <sup>b</sup>	.000
I feel supported and understood when I talk about my pain with my health care provider:- Other	Male	1	1.00	.	.
I feel supported and understood when I talk about my pain with my health care provider:- Other	Female	2	1.00	.000	.000

a. t cannot be computed because at least one of the groups is empty.

### Group Statistics

Q 16.	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
I feel supported and understood when I talk about my pain with my friends & family:- Strongly Agree	Male	4	1.00	.000 <sup>a</sup>	.000
	Female	11	1.00	.000 <sup>a</sup>	.000
I feel supported and understood when I talk about my pain with my friends & family:-Agree	Male	14	1.00	.000 <sup>a</sup>	.000
	Female	58	1.00	.000 <sup>a</sup>	.000
I feel supported and understood when I talk about my pain with my friends & family:- Neither Agree nor Disagree	Male	10	1.00	.000 <sup>a</sup>	.000
	Female	29	1.00	.000 <sup>a</sup>	.000
I feel supported and understood when I talk about my pain with my friends & family:- Disagree	Male	6	1.00	.000 <sup>a</sup>	.000
	Female	24	1.00	.000 <sup>a</sup>	.000

I feel supported and understood when I talk about my pain with my friends & family:- Strongly Disagree	Male	2	1.00	.000 <sup>a</sup>	.000
	Female	7	1.00	.000 <sup>a</sup>	.000
I feel supported and understood when I talk about my pain with my friends & family:-Other	Male	2	1.00	.000 <sup>a</sup>	.000
	Female	5	1.00	.000 <sup>a</sup>	.000

a. t cannot be computed because the standard deviations of both groups are 0.

### Group Statistics

Q 17. Health Care Provider	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Information about my chronic pain condition	Male	35	3.83	1.272	.215
	Female	127	3.99	1.165	.103
	Male	35	4.46	.741	.125



On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Information about my treatment plan	Female	126	4.26	.956	.085
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...-Support for my emotional well-being	Male Female	35 127	3.43 3.61	1.313 1.310	.222 .116
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...-Empathy regarding the debilitating impacts of chronic pain	Male Female	35 127	3.51 3.91	1.292 1.113	.218 .099
	Male	35	3.71	1.202	.203

On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Opportunity for me to talk about my pain, in my own words	Female	126	3.67	1.277	.114
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Q. 17 Rank following items you would like your health care provider to offer you:

### Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Information about my chronic pain condition	164	1	5	3.96	1.182

On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Information about my treatment plan	163	1	5	4.31	.913
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...-Support for my emotional well- being	164	1	5	3.58	1.306
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...-Empathy regarding the debilitating impacts of chronic pain	164	1	5	3.84	1.161

On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Information about my treatment plan	164	1	5	2.30	1.335
Valid N (listwise)	163				

### Group Statistics

Q 18: Family & Friends	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...-Support for my emotional well- being	Male	35	4.29	.860	.145
	Female	126	4.49	.746	.066
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...-Empathy regarding the debilitating impacts of chronic pain	Male	35	4.14	1.141	.193
	Female	127	4.48	.834	.074
On a scale of 1 to 5, with 1 representing	Male	34	3.38	1.256	.215

little importance and 5 representing great importance,...- Opportunity for me to talk about my pain, in my own words	Female	126	3.99	.984	.088
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Information about my chronic pain condition	Male	35	1.89	1.255	.212
	Female	127	2.41	1.329	.118
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Information about my treatment plan	Male	35	1.97	1.361	.230
	Female	127	2.36	1.307	.116

Q. 18 Rank following items you would like your family and friends to offer you:

### Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...-Support for my emotional well-being	163	1	5	4.45	.771

On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...-Empathy regarding the debilitating impacts of chronic pain	164	1	5	4.41	.913
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Opportunity for me to talk about my pain, in my own words	162	1	5	3.87	1.070
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Information about my chronic pain condition	164	1	5	2.32	1.337
On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance,...- Information about my treatment plan	164	1	5	2.30	1.335
Valid N (listwise)	162				

### Group Statistics

Q. 19 Health Care Provider	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
	Male	24	1.00	.000 <sup>a</sup>	.000

To better understand my chronic pain, I wish my health care provider would ask me more about how...-impacts my daily activities	Female	101	1.00	.000 <sup>a</sup>	.000
To better understand my chronic pain, I wish my health care provider would ask me more about how...-impacts my social and family relationships	Male Female	21 89	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
To better understand my chronic pain, I wish my health care provider would ask me more about how...-impacts my work responsibilities	Male Female	24 78	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
	Male	22	1.00	.000 <sup>a</sup>	.000

To better understand my chronic pain, I wish my health care provider would ask me more about how...-impacts my self-image and self-esteem	Female	71	1.00	.000 <sup>a</sup>	.000
To better understand my chronic pain, I wish my health care provider would ask me more about how...-impacts my goals and dreams	Male	19	1.00	.000 <sup>a</sup>	.000
To better understand my chronic pain, I wish my health care provider would ask me more about how...-impacts my goals and dreams	Female	80	1.00	.000 <sup>a</sup>	.000
To better understand my chronic pain, I wish my health care provider would ask me more about how...-nothing, I don't want to talk to them about any of these	Male	1	1.00	.	.
	Female	3	1.00	.000	.000
	Male	4	1.00	.000 <sup>a</sup>	.000



To better understand my chronic pain, I wish my health care provider would ask me more about how...-Other	Female	13	1.00	.000 <sup>a</sup>	.000
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a. t cannot be computed because the standard deviations of both groups are 0.

### Group Statistics

q. 20 Family & Friends	19. Please indicate your gender:	N	Mean	Std. Deviation	Std. Error Mean
To better understand my chronic pain, I wish my family and friends would ask me more about: (cho...-impacts my daily activities	Male	17	1.00	.000 <sup>a</sup>	.000
	Female	84	1.00	.000 <sup>a</sup>	.000
	Male	19	1.00	.000 <sup>a</sup>	.000

To better understand my chronic pain, I wish my family and friends would ask me more about: (cho...-impacts my social and family relationships	Female	76	1.00	.000 <sup>a</sup>	.000
To better understand my chronic pain, I wish my family and friends would ask me more about: (cho...-impacts my work responsibilities	Male Female	14 44	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
To better understand my chronic pain, I wish my family and friends would ask me more about: (cho...-impacts my self-image and self-esteem	Male Female	18 70	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
	Male	18	1.00	.000 <sup>a</sup>	.000

To better understand my chronic pain, I wish my family and friends would ask me more about: (cho...-impacts my goals and dreams	Female	74	1.00	.000 <sup>a</sup>	.000
To better understand my chronic pain, I wish my family and friends would ask me more about: (cho...-nothing, I don't want to talk to them about any of these	Male Female	7 17	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000
To better understand my chronic pain, I wish my family and friends would ask me more about: (cho...-Other	Male Female	5 7	1.00 1.00	.000 <sup>a</sup> .000 <sup>a</sup>	.000 .000

a. t cannot be computed because the standard deviations of both groups are 0.

## Appendix N: Independent Samples T-Test

T-test for questions 17 and 18

Q. 17 On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance, please rank the following items you would like your **health care provider** to offer you:

### Information about my chronic pain condition

Equal variances assumed

F	Sig	t	df	P value	Mean Diff	Std. Error Diff	95% Confid.	
							Upper	Lower
.838	.361	-.721	160	.472	-.164	.227	-.612	.284

Equal variances not assumed

		-.686	50.815	.496	-.164	.238	-.642	.315
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### Information about my treatment plan

Equal variances assumed

F	Sig	t	df	P value	Mean Diff	Std. Error Diff	95% Confid.	
							Upper	Lower
1.170	.281	1.117	159	.266	.195	.175	-.150	.540

Equal variances not assumed

		1.288	68.717	.202	.195	.152	-.107	.498
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### Support for my emotional well-being

Equal variances assumed

F	Sig	t	df	P value	Mean Diff	Std. Error Diff	95% Confid.	
							Upper	Lower

.003	.958	-7.10	160	.479		-1.78	.250	-6.72	.316
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Equal variances not assumed

		-7.10	54.139	.481		-1.78	.250	-6.80	.324
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**Empathy regarding the debilitating impacts of chronic pain**

Equal variances assumed

<b>F</b>	<b>Sig</b>	<b>t</b>	<b>df</b>	<b>P value</b>	<b>Mean Diff</b>	<b>Std. Error Diff</b>	<b>95% Confid.</b>	
							<b>Upper</b>	<b>Lower</b>
2.754	.099	-1.813	160	.072	-.399	.220	-.834	.036

Equal variances not assumed

		-1.665	48.778	.102		-.399	.240	-.881	.083
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**Opportunity for me to talk about my pain, in my own words**

Equal variances assumed

<b>F</b>	<b>Sig</b>	<b>t</b>	<b>df</b>	<b>P value</b>	<b>Mean Diff</b>	<b>Std. Error Diff</b>	<b>95% Confid.</b>	
							<b>Upper</b>	<b>Lower</b>
1.045	.308	.198	159	.844	.048	.241	-.429	.524

Equal variances not assumed

		.204	57.143	.839		.048	.233	-.419	.514
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Q18 On a scale of 1 to 5, with 1 representing little importance and 5 representing great importance, please rank the following items you would like **your family and friends** to offer you:

**Support for my emotional well-being**

Equal variances assumed

F	Sig	t	df	P value	Mean Diff	Std. Error Diff	95% Confid.	
							Upper	Lower
2.078	.151	-1.400	159	.164	-.206	.147	-.497	.085

Equal variances not assumed

-1.291	49.101	.203	-.206	.160	-.527	.115
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**Empathy regarding the debilitating impacts of chronic pain**

Equal variances assumed

F	Sig	t	df	P value	Mean Diff	Std. Error Diff	95% Confid.	
							Upper	Lower
10.140	.002	-1.946	160	.053	-.337	.173	-.680	.005

Equal variances not assumed

-1.633	44.491	.109	-.337	.207	-.754	.079
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**Opportunity for me to talk about my pain, in my own words**

Equal variances assumed

F	Sig	t	df	P value	Mean Diff	Std. Error Diff	95% Confid.	
							Upper	Lower
3.550	.061	-3.015	158	.003	-.610	.202	-1.009	-.210

Equal variances not assumed

-2.622 44.517 .012      -.610      .232      -1.078      -.141

**Information about my chronic pain condition**

Equal variances assumed

<b>F</b>	<b>Sig</b>	<b>t</b>	<b>df</b>	<b>P value</b>	<b>Mean Diff</b>	<b>Std. Error Diff</b>	<b>95% Confid.</b>	
							<b>Upper</b>	<b>Lower</b>
1.245	.266	-2.088	160	.038	.524	.251	-1.019	-.028

Equal variances not assumed

-2.158 56.820 .035      -.524      .243      -1.010      -.038

**Information about my treatment plan**

Equal variances assumed

<b>F</b>	<b>Sig</b>	<b>t</b>	<b>df</b>	<b>P value</b>	<b>Mean Diff</b>	<b>Std. Error Diff</b>	<b>95% Confid.</b>	
							<b>Upper</b>	<b>Lower</b>
.001	.977	-1.552	160	.123	-.391	.252	-.888	.106

Equal variances not assumed

-1.517 52.574 .135      -.391      .258      -.908      .126

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